Community Outreach Specialist
and Lay Health Advisor Training

The following materials are examples of the training manuals used in the North Carolina Breast Cancer Screening Program (NC-BCSP). The Original Training Manual includes the Community Outreach Specialist and LHA Training.

Each training was county-specific and included current brochures (not shown) from organizations such as the National Cancer Institute (NCI), Centers for Disease Control and Prevention (CDC), and the American Cancer Society (ACS).

Most of the example materials included in this packet are from Washington County, North Carolina. NC-BCSP took place in five counties. Materials were targeted to each county.

The following materials include:

- Original Training Manual (denoted with cover page)
  - In use during the entire evaluation period (1992-2000)
- New Training Manual (denoted with cover page)
  - In the final years of NCI funding, NC-BCSP worked closely with community organizations to develop strategies for sustaining the project. As part of this process, NC-BCSP revised and updated the LHA Training Manual. Our goal was to create a training curriculum that anyone could use “off the shelf,” even with minimal training expertise.

Community Outreach Specialist and Lay Health Advisor Training

ORIGINAL TRAINING MANUAL

OVERVIEW OF NORTH CAROLINA BCSP

A. WHAT IS NORH CAROLINA BCSP?

North Carolina Breast Cancer Screening Program (NCBCSP) represents a group of state and local public health agencies and universities working together to increase mammography screening among African American Women. The program is being conducted in Beaufort, Bertie, Martin, Tyrrell, and Washington conties. BCSP activities are classfied under three distinct intervention components: Outreach, Inreach, and Access.

Outreach activities include broadening community awareness of and support for breast cancer screening through the use of health educators and locally trained community women serving as "lay health advisors" to the program.

Inreach activities focus on assisting local Health Departments and Community Health Centers to organize, expand, and improve their breast cancer screening activities, the restructuring of clinic policies and procedures, and the training of staff.

Access attempts to reduce structural barriers, such as cost and inadequate transportation, that prevent low income women from obtaining mammograms.

B. WHO IS BCSP?

UNC Administrative Team

Jo Anne Earp, Sc.D.	Principal Investigator
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Margo Michaels	
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Barbara Rimer, Dr.PH (Duke University)	Co-Investigator
Irene Tessaro, Dr.PH (Duke University)	
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Monica	

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Eva Hill	MTW Health District
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Jim Mitchell, Ph.D.	Co-Investigator
Holly Matthews, Ph.D.	Co-Investigator
Michael O'Malley, M.S.P.H.	
Kathy Whaley	
Shelia Ellis	

C. WHAT IS THE ROLE OF THE HEALTH EDUCATOR?

Research Team
at Universities

Data collection

Health Educator

Health Clinics
[Inreach]

Community Health Centers

Community
[Outreach]

Focus Groups
Lay Health Advisors
Community Activities

The health educator is a very important part of North Carolina BCSP, she is the focal point of the project. The health educator is responsible for performing both Inreach and Outreach activities as well as some administrative tasks.

As a health educator, you are a link between the people of your community and the local health clinic or rural health center. You are also a link between the activities in your county and the team in Chapel Hill. [The following chapters will outline your activities in more detail]

SECTION II:

OUTREACH

A majority of your time as the Health Educator for your county will be spent performing Outreach activities. These activities will include conducting Focus Groups, recruiting, and training Lay Health Advisors, and organizing community activities.

The first chapter in this section provides some information on breast cancer, mammography, and breast self-exams. There is additional breast cancer information in the Lay Health Advisor training manual.

Chapter 2 is your Community Resource File. It is designed to help you start connecting with the important organizations, women, and service agencies in your community.

Chapter 3 is all about Focus Groups: how to conduct them, how many to conduct, and how to recruit participants for focus groups.

Chapter 4 will help you identify, recruit, and train Lay Health Advisors in your county.

Chapter 5 provides you with information about organizing community activities such as having the mobile mammography van come to your local church to screen the women for breast cancer.

CHAPTER 1

BREAST CANCER AND MAMMOGRAPHY

As a health educator you will be a resource for information about mammography and breast cancer in your county. Although the Lay Health Advisors will be a resource within their own communities, they will turn to you for more technical and advanced information. The following guide gives you the necessary information to help you to answer questions and provide technical information. This information supplements what is in the back of the Lay Health Advisor's Manual. The information provided here has been reprinted from the National Cancer institute.

In this chapter you will find information on:

Facts about breast cancer and mammography specifically for African American women;

Myths and Facts about breast cancer and mammography;

Questions and answers about breast cancer, mammography, and what to do if cancer is found; and

Breast self-examination.

FACTS ABOUT BREAST CANCER, MAMMOGRAPHY, AND AFRICAN AMERICAN WOMEN

The following is a quick reference for facts about breast cancer and mammography and how both uniquely impact African American women.

ALL AFRICAN AMERICAN WOMEN ARE AT RISK

- Breast cancer is the leading cause of cancer death for African American women.

- All women are at risk for developing breast cancer, including those with no family history of the disease, and the risk increases with age. One in nine U.S. women will develop breast cancer.

EARLY DETECTION SAVES LIVES

- A special x-ray technique called mammography is the most effective way to find breast cancer in its earliest stages-up to two years before a lump can even be felt.

- Up to 90 percent of women whose breast cancer is found and treated early, before it has spread beyond the breast, will survive. Early detection also means that less extensive surgery can be used, often saving the breast itself.

- The National Cancer Institute (NCI) and 12 other leading medical organizations, including the National Medical Association (an organization of African American doctors) recommend that : Beginning at age 40, women should have a mammogram every 1 to 2 years and an annual breast exam by a doctor. Starting at age 50, women should have annual mammograms along with the yearly breast exams by their doctors. NCI also recommends that all women do monthly breast self-exams.

- Unfortunately, few Black American women know about and take advantage of mammography. Only 58 percent of Black American women 40 and older have ever had a screening mammogram to detect breast cancer, compared with 65 percent of all white women in that age group.

MAMMOGRAPHY IS SIMPLE

- Two pictures are taken of each breast--one from the top and one from the side. The breasts are placed between plastic plates and flattened slightly to get a clear picture. The procedure may be a little uncomfortable, but it is not painful.

THE RISK IS SMALL

- The amount of radiation produced by mammography is extremely low.

- Women can ask their doctors if mammography center personnel are well trained, experienced, and use special mammography equipment.

THE EXAM IS EASY TO ARRANGE

- Doctors can arrange for a mammogram or in some counties women can arrange for the mammograms themselves. Women can get mammograms at a local hospital, health clinic, or mobil van. The facility must meet certain quality standards.

- The exam should cost between $50 and $150. If cost is a concern, various health agencies, organizations, and women's support groups across the country provide referrals to low-cost or free mammography services.

MYTHS AND FACTS

There are many myths about breast cancer and mammography. Because of the myths and misinformation nearly one third of the women who should have mammograms do not get them. Many more don't get them often enough.

One of the goals of BCSP is to increase older African American women's knowledge of the facts about breast cancer and mammography. The following is a list of myths which are followed by the facts about breast cancer and mammography.

MYTH 1: There is no history of breast cancer in my family, so I don't need to worry about it.

FACT: While a family history of the disease is one risk factor, 80 percent of women who develop breast cancer have no history of the disease in their families.

MYTH 2: I don't need a mammogram if I don't have any symptoms.

FACT: Mammography can detect breast cancers when they are extremely small, up to two years before they can be felt by a woman or her doctor. When detected and treated early, breast cancer need not be life-threatening.

MYTH 3: If my doctor didn't recommend a mammogram, I don't need one.

FACT: Although most doctors do recommend a mammogram for their women patients 40 and older, not all do. Don't wait. The guidelines adopted by the National Cancer Institure and 12 leading medical organizations are:

- Beginning at age 40 you should have a mammogram every 1 to 2 years.
- When you turn 50 you should have a mammogram every year.
- Your doctor/nurse should give you a breast exam once a year.
- NCI also recommends that women do monthly breast self-exams.

These guidelines apply only to women who do not have any symptoms or signs of breast cancer, such as a lump or other change in the breast. If you have any symptoms, contact your doctor immediately.

MYTH 4: I had one normal mammogram, so I don't need anothe

FACT: If you have already had one mammogram, that's a terrific start. But once is not enough. Every woman age 40 and older should include mammograms as part of her regular healthcare routine.

QUESTIONS AND ANSWERS ABOUT MAMMOGRAPHY AND BREAST CANCER

The following is a list of questions commonly asked about breast cancer and mammography. The answers provided will increase your knowledge as well as help you give more information about breast cancer and mammography to women in your community.

BREAST CANCER

1. **What are the risk factors for developing breast cancer an how can women protect themselves against breast cance**

   Simply getting older and being a woman puts you at risk; two thirds of cases occur in women over age 50. The risk is also increased if a woman has a history of breast cancer in her family; has never had children; had her first child after age 30 began menstruating before age 12; began menopause after age 55; or eats a high fat diet,

   There is no way to prevent breast cancer, but the best protection is early detection and prompt treatment. Early detection includes regular screening mammograms, breast exams by a physician or nurse, and monthly breast self-exams.

3. **What are the warning signs of breast cancer?**

   The most common sign is a lump or thickening in the breast. Other signs are a change in the size or shape of the breast discharge from the nipple, or a change in the color or texture of the skin of the breast or skin around the nipple (areola). **However, often there aren't any tangible signs of breast cancer until the dise has progressed into its advanced stages; that's why a mammogram, which can detect breast cancer before it ca be seen or felt, is so important.**

MAMMOGRAPHY: THE SCREENING PROCEDURE

1. Who will pay for breast cancer screening?

The mammography screening should cost between $50 and $150. If cost is a concern, various health agencies, organizations, and women's support groups across the country provide referrals to low cost or free mammography services.

Insurance coverage for mammography screening is becoming more widespread. Medicare pays a limited amount toward mammography screening for its beneficiaries (They pay for one mammogram every two years). Also, more than 30 states now require that insurance companies provide some form of mammography coverage.

2. How can women be sure they are getting high-quality mammograms?

If a mammography facility is accredited by the American College of Radiology, its machines and staff have met specific quality standards. If a woman cannot find an accredited facility near her home, there are several questions to ask to insure that the chosen mammography facility is high quality. The facility should answer "yes" to all of the following questions:

- Does the facility use machines specifically designed for mammography? These are called "dedicated" mammography machines.
- Are the mammograms given by a registered technologist?
- Is the radiologist specially trained to read mammograms?
- Does the facility provide mammograms as part of its regular practice?
- Is the mammography machine properly adjusted at least once a year?

3. How can a woman prepare for a mammogram?

First, she should check with the office where she'll be having the mammogram for any specific instructions. In general, preparation involves the following:

- She shouldn't wear any deoderant, perfume, powders or ointments of any sort in the underarm area or on the breast on the day of the exam. These products may cause shadows to appear on the mammogram.

- She should wear a blouse with a skirt or slacks, rather than a dress, to the mammography facility. She will have to undress above the waist for the exam.

- If possible, she shouldn't schedule a mammogram near her menstral period, since her breasts may be more tender than usual at this time. The exam should not be painful, although the compression of the breast during the exam may cause some discomfort.

4. Who will give the mammogram?

A trained radiologic technologist positions one breast between two plastic plates that compress the breast, spreading it out so that the x-rays can produce as precise an image as possible. She then takes the x-rays for about the breast and from the side. The procedure is repeated for the other breast and only takes a few minutes.

Then a specially trained physician, called a radiologist, reads the mammogram to determine if any suspicious areas exist.

5. How will the results of the examination be delivered?

The radiologist studies the mammogram and reports the findings directy to the woman or to her physician, who will contact her with these results. Either the radioloist or the physician will tell her if there is a need for further test or examinations.

Women should keep in mind that even if a biopsy is recommended based on the results of a mammogram, four out of five lumps or suspicious findings turn out to be benign (not cancer).

6. What are calcifications?

Calcifications are small calcium deposits in the breast that are found only by mammography.

Microcalcifications are tiny specks of calcium which may be found in an area of rapidly dividing cells. When many of these are seen in one area, they are referred to as a cluster and may indicate a small cancer. About half of the cancers detected by mammography appear as a cluster of microcalcifications, the other half appear as lumps.

Microcalcificaitons are coarse calcium deposits which are found in about half of all women over age 50 and are associated with benign conditions.

IF BREAST CANCER IS FOUND....

1. What is the procedure if a lump is found?

In some cases, the physician may order an aspiration biopsy (removal of fluid) of a breast lump. In other cases a tissue biopsy is recommended. This surgical removal and microscopic examination of the lump is the only way to determine whether cancer cells are present. If the biopsy indicates the presence of cancer cells, the woman and her physician will confer about treatment options.

2. How is breast cancer treated?

Ther are four standard ways to treat breast cancer: surgery, radiation therapy, hormonal therapy, and chemotherapy. Several treatments may be combined and specific treatment recommendations depend on the type and location of the tumor, the stage at which it has been detected, and the patient's age and general health.

- **Surgery.** The surgical procedures used to treat breast cancer include lumpectomy plus radiation therapy, and modified radical mastectomy. In lumpectomy, the tumor and a rim of surrounding normal tissue are removed. Modified radical mastectomy involves removing the breast, the lining over the chest muscles, and the axillary (under arm) lymph nodes.

- **Radiation Therapy.** During this treatment process, either ar outside source or a radioactive implant administer high-energy rays to stop the growth of cancer cells.

- **Hormonal Therapy.** In hormonal therapy, drugs block the availability of hormones that cancer cells need to grow.

- **Chemotherapy.**Chemotherapy uses powerful drugs to stop the growth of cancer cells.

3. Can breast cancer recur after treatment?

Yes. That is why it is important for women who have been treated for breast cancer to schedule follow-up examinations and mammograms as recommended by a physician.

4. What can be used to replace the breast after surgery?

If mastectomy is the treatment a woman and her physician choose, the patient's breast will be removed. To look and feel as natural as possible after this surgery, women can choose to wear prosthesis (artificial replacement) or to undergo breast reconstruction through plastic surgery.

5. What kinds of information and support are available?

There are many local and national programs available to help women learn about and cope with breast cancer. The support of the family, other women who have had similar experiences, and particularly of those who are trained to assist women recovering from breast surgery, can be extremely helpful.

For information about specific programs and contacts, call the National Cancer Insititute's Cancer information Service at 1-800-4-CANCER.

6. What can family members and friends do to help?

Family members and friends concerned about the health of women close to them can help by encouraging them to learn the facts about breast cancer and the importance of early detection. They can also remind women to get regular mammograms, receive yearly examinations by a physician or nurse and do monthly breast self-examinations.

BREAST SELF-EXAMINATIONS

Although the focus of BCSP is on mammography screening for breast cancer, each woman should be encouraged to perform monthly breast self-examinations (BSE) and to receive clinical breast exams annually. The clinical breast exam is performed by a physician or a nurse in the clinic, this examination is different from a mammogram. In a clinical breast exam, the physician or nurse checks the breasts much like a woman checks her own breasts in a breast self-exam described below.

Performing monthly BSE allows you to get used to the consistency of your own breasts so that you can detect more subtle changes and seek medical advice sooner. **Remember that monthly breast self-exams and annual clinical breast exams are <u>not</u> a substitute for regular mammograms.** If a woman performs all three, she increases her chances of detecting a lump while it is still small, this means her chances of surviving breast cancer are improved.

Breast-Self Examination

You should examine your breasts while standing up and lying down. Standing up in front of a mirror allows you to look at the size and shape of each breast. Lying down allows you to press the breast against the rib cage to feel any lumps.

Look for nipple changes, sores, reddening of the skin, discharge or crusting. A nipple that retracts inward can be a danger signal, although this is normal for many women.

Standing in front of a mirror with your arms relaxed at your sides, note the shape and size of each breast. (One is usually slightly larger than the other but the shape should be about the same.) If you note any change, dimpling, puckering, or indentation, you should see your Health Care Professional. Raise your arms over your head, press your palms together and again check each breast. Feel each breast in the manner described below. The exam will be easier in the shower when your skin is wet.

The procedure for feeling the breast is the same for lying or standing. Raise your right hand over your head and use your left hand to feel your right breast. Reverse this to feel the left breast. Keep your middle three fingers flat and press gently inward, moving your hand in a circular motion. Begin at the upper corner of the breast near the armpit. Move the fingers down the outside of the bvreast and back up the breast in a strip fashion until you have covered the entire breast. Compressing your breast between thumb and fingers may cause you to feel a "lump" that doesn't exist.

Next, using the flat part of your fingers, feel under your arm. Tiny glands called lymph nodes are located there. If something is wrong within the breast, these may be enlarged. Remember, however, that infections within the body can also cause them to enlarge.

Many women have a normal thickening or ridge of firm tissue under the lower curve of the breast and at its attachment to the chest wall. Large milk ducts can be felt as a ring of "lumps" at the outer edge of the dark nipple area. Any lump or other changes found in one breast only, especially in the upper outer quadrant, is more likely to be seriious.

Breast Self-Examination Checklist

1. Check nipples for:

_____cysts, eczyma, ulcers
_____discharge, bleeding
_____change in shape (inversion, flattening, dimpling)
_____change in nipple location

2. Check breast shape for:

_____change in size
_____change in contour
_____bulges, flattening, indentation (including armpit area)

3. Check breast surface for:

_____puckered, orange peel skin
_____dimples, bulges
_____moles that have enlarged or darkened
_____lumps or thickening
_____sores, ulcerations

CHAPTER 2

COMMUNITY RESOURCE FILE

This chapter is designed to help get you started in your Outreach Activities for BCSP. We have provided some suggestions of people and agencies you'll want to contact in your county. But we also want you to identify organizations unique to your county that will help you get to know the women in your community.

COMMUNITY RESOURCES

1. What are the names of the Black Churches in the communities in this county?

Name of Church	Name of Minister	Days Minister at Church

phone number of church

In what ways can the church help with BCSP?_____

Name of Church	Name of Minister	Days Minister at Church

phone number of church

In what ways can the church help with BCSP?_____

Name of Church	Name of Minister	Days Minister at Church

phone number of church

In what ways can the church help with BCSP?_____

Name of Church _____ Name of Minister _____ Days Minister at Church _____

phone number of church _____

In what ways can the church help with BCSP? _____

Name of Church _____ Name of Minister _____ Days Minister at Church _____

phone number of church _____

In what ways can the church help with BCSP? _____

Name of Church _____ Name of Minister _____ Days Minister at Church _____

phone number of church _____

In what ways can the church help with BCSP? _____

2. What are some of the groups that meet at the church? (i.e. Sororities or Missionary Societies)

Name of Group	Group Leader	Phone Number

Name of Group	Group Leader	Phone Number
Name of Group	Group Leader	Phone Number

3. Where is the local Medicare office?

Name of Contact at Medicare _____ Phone Number _____

4. Where is the local Medicaid office?

Name of Contact at Medicaid _____ Phone Number _____

5. Where is the local American Cancer Society Office?

Name of Contact at ACS _____ Phone Number _____

6. Where does the local 4-H group meet? Do they have a Home Economics Division?

Name of Contact at 4-H _____ Phone Number _____

Name of Contact at Home Economics Div. _____ Phone Number _____

7. Where is the local Interagency Council?

Name of Contact at Interagency Council _____ Phone Number _____

8. Who are other groups in your county who can provide support for BCSP?

Name of Agency _____ Phone Number _____

Name of Contact at the Agency _____ Phone Number _____

Name of Agency _____ Phone Number _____

Name of Contact at the Agency _____ Phone Number _____

Name of Agency _____ Phone Number _____

Name of Contact at the Agency _____ Phone Number _____

Name of Agency

Phone Number

Name of Contact at the Agency

Phone Number

Name of Agency

Phone Number

Name of Contact at the Agency

Phone Number

Name of Agency

Phone Number

Name of Contact at the Agency

Phone Number

BEAUFORT CO DSS
P. O. BOX 1358
WASHINGTON, NC 27889

PAT COPEHART
946-6591

Service(s): CHORE
HOMEMAKER HOME HEALTH AIDE

TRI COUNTY HEALTH SERVICES
P. O. BOX 40
AURORA, NC 27806

EDWARD WILDER
322-7181

Service(s): CHORE
HOMEMAKER HOME HEALTH AIDE
RESPITE
HOME HEALTH - SKILLED NURSING

BEAUFORT CO COUNCIL ON AGING
111 WEST SECOND STREET
WASHINGTON, NC 27889

SYLVIA BROOKS
946-7090

Service(s): TRANSPORTATION-GENERAL
TRANSPORTATION-MEDICAL
CONGREGATE NUTRITION-CATERED
HOME DELIVERED MEALS

Bertie County

BERTIE CO COUNCIL ON AGING
P. O. BOX 644
WINDSOR, NC 27983

SHARLENE BRANDT
794-2028

Service(s): TRANSPORTATION-GENERAL
TRANSPORTATION-MEDICAL
CONGREGATE NUTRITION-CATERED
HOME DELIVERED MEALS
INFORMATION & REFERRAL

Martin County

Region: Q

TOWN OF WILLIAMSTON
P. O. BOX 1023
WILLIAMSTON, NC 27892

SYLVIA P. WYNNE
792-1027

Service(s): RESPITE
TRANSPORTATION-GENERAL
TRANSPORTATION-MEDICAL
CONGREGATE NUTRITION-CATERED
HOME DELIVERED MEALS
SENIOR CENTER OPERATIONS

MARTIN-TYRRELL-WASHINGTON DISTRICT HEALTH DEPARTMENT
P. O. BOX 546
WILLIAMSTON, NC 27892

JUDITH WRIGHT
792-7811

Service(s): HOMEMAKER HOME HEALTH AIDE
HOME HEALTH-SKILLED NURSING

TYRRELL CO DSS
P. O. BOX 449
COLUMBIA, NC 27925

HARRY FOARD
796-3421

Service(s): CHORE
RESPITE

TYRRELL CO FOCAL POINT ON AGING
P. O. BOX 426
COLUMBIA, NC 27925

WILLIAM BATEMAN
796-0365

Service(s): TRANSPORTATION-GENERAL
TRANSPORTATION-NUTRITION

MARTIN-TYRRELL-WASHINGTON DISTRICT HEALTH DEPARTMENT
P. O. BOX 396
PLYMOUTH, NC 27962

JEAN ASKEW
793-3023

Service(s): HOMEMAKER HOME HEALTH AIDE

PAMLICO SOUND LEGAL SERVICES
P. O. BOX 1167
NEW BERN, NC 28560

WILLIE DAWSON
637-9502

Service(s): LEGAL

ALBEMARLE COMMISSION
P. O. BOX 646
HERTFORD, NC 27944

DARLENE HARRELL
426-5753

Service(s): CONGREGATE NUTRITION-CATERED
HOME DELIVERED

Washington County

Region: Q

WASHINGTON CO DSS
P. O. BOX 10
PLYMOUTH, NC 27963

JERRY RHODES
793-4041

Service(s): CHORE
RESPITE
TRANSPORTATION-NUTRITION
TRANSPORTATION-MEDICAL

MARTIN-TYRRELL-WASHINGTON DISTRICT HEALTH DEPARTMENT
P. O. BOX 396
PLYMOUTH, NC 27962

JEAN ASKEW
793-3023

Service(s): HOMEMAKER HOME HEALTH AIDE

PAMLICO SOUND LEGAL SERVICES
P. O. BOX 1167
NEW BERN, NC 28560

WILLIE DAWSON
637-9502

Service(s): LEGAL

ALBEMARLE COMMISSION
P. O. BOX 646
HERTFORD, NC 27944

DARLENE HARRELL
426-5753

Service(s): CONGREGATE NUTRITION-CATERED
HOME DELIVERED

APPENDIX A - ACCREDITED MOBILE MAMMOGRAPHY VANS IN NORTH CAROLINA

* Greene County Health Care Inc.
  PO Box 658
  Snow Hill, NC 28580

  302 N. Greene Street
  Snow Hill, NC

* Mobile Diagnostic Services
  1309-10 N. Elm St.
  Greensboro, NC 27401

* Southeastern Radiology, PA
  3801 W. Market St.
  Greensboro, NC 27407

* Mecklenburg Health Department Mobile Van
  249 Billingsley Road
  Charlotte, NC 28211

* Metrolina Outreach Mammo.
  8701 Mallard Creek Road
  Charlotte, NC 28262

* Carolina Screening Mammo.
  212 Finley Road
  Chapel Hill, NC 27514

* Lumberton Rad. Mobile Van
  209 W. 27th Street
  Lumberton, NC 28359

CHAPTER 3

FOCUS GROUPS

A focus group is comprised of people who will benefit from the program you are planning. Essentially, you will be getting feedback from the women of your county about what will help BCSP work in their community. The type of information you are likely to gather may include unconsious barriers to having mammograms.

This chapter mainly deals with how to conduct a focus group. We have given you information on criteria for focus groups; a step by step planning guide; a sample focus group member profile; and a moderator's guide for BCSP focus groups.

Dr. Geni Eng, Dr. Irene Tessaro, and others will be providing an indepth training for you on how to conduct focus groups.

BCSP FOCUS GROUP CRITERIA

- Groups should consist of all African American women.

- You will conduct two focus groups. One group will consist of women age 50-65, another will consist of women age 65 and older.

- Six of the women in each group will have had a mammogram in the last two years; six of the women in each group will never have had a mammogram or will have not had one in the last three years. Thus, each focus group will consist of a total of twelve women.

- You will want to recruit women who are part of formal networks, for example from churches or missionary societies.

The following questions will help you screen women for Focus Groups.

QUESTIONS:

1. How old are you?

   Younger than 50 ---------- ➢**NOT ELIGIBLE**

   50-65 ---------- ➢**ELIGIBLE FOR GROUP 1**

   65 or older ---------- ➢**ELIGIBLE FOR GROUP 2**

2. Have you ever had a mammogram?

   No ---------- ➢**PUT IN APPROPRIATE AGE GROUP IF SLOT AVAILABLE**

3. **If ever had mammogram:** How long ago was your last mammogram?

   Mammogram in last 2 years---------- ➢**PUT IN APPROPRIATE AGE GROUP IF SLOT AVAILABLE**

   Mammogram 3 years or more ago ------- ➢**PUT IN APPROPRIATE AGE GROUP IF SLOT AVAILABLE**

   Mammogram between 2-3 years ago ---- ➢**NOT ELIGIBLE**

If woman is not eligible, explain that we only want to talk with women:

Over age 50
with a particular mammogram history

If slot is unavailable, explain that we have enough women in her age group or enough women with a particular mammography history

GROUP 1
(AGES 50-65)

GROUP 2
(AGES 65+)

Had a mammogram in the last 2 years

1. ----------
2. ----------
3. ----------
4. ----------
5. ----------
6. ----------

1. ----------
2. ----------
3. ----------
4. ----------
5. ----------
6. ----------

Never had a mammogram or not in last 5 years

1. ----------
2. ----------
3. ----------
4. ----------
5. ----------
6. ----------

1. ----------
2. ----------
3. ----------
4. ----------
5. ----------
6. ----------

STEP BY STEP FOCUS GROUP PLANNING GUIDE

This guide primarily covers the "nuts and bolts" of arranging a focus group. There are many small tasks that need to be accomplished in order for a focus group to go smoothly. For more detailed information on actually conducting focus groups consult the training materials and your notes from the training conducted by Geni Eng.

TWO WEEKS IN ADVANCE

1. Identify potential focus group sites. Find out the type of people who are found there, the times of day, the name and number of the contact person (if there is one), and other information. Before you begin to make arrangements for a focus group consult with Geni to make sure that the focus group will meet BCSP research objectives.

2. Visit the potential focus group site and meet with the contact person. Explain BCSP and the focus group to him or her. Explain exactly what will take place on the day of the focus group. Be open to receiving advice from them about what will and won't work with that particular group of people. Set a date and time.

3. The contact person (coordinator, social worker, or whoever) should not be in the room during the focus group. You need to make this clear to him or her from the beginning.

4. If the site is connected to a non-profit organization then we can donate $50 to that organization. We will need a trustworthy person to sign a receipt for the money. This arrangement needs to be set in place in advance.

5. Reserve an appropriate room at the site where people will be gathered. The room should be private, have enough chairs for everyone, a table if possible, and an electrical outlet for the tape recorder. Always try to examine the room in advance. It is a good idea to test the electrical outlet. You may need to arrange for extra chairs or other things.

A WEEK IN ADVANCE

1. Call your local supermarket and order a party platter from the Deli. The food budget per group is limited to $50. If you decide to provide another type of refreshment then make those arrangements.

2. Get the check to take to each focus group from Linda. You will need to keep detailed records on whom you make the check out to and the check number.

3. The group leader and the notetaker should meet and tailor the focus group "Discussion Guide" to match the characteristics of the group. This may mean changing the slant of some questions. Try to become familiar with the discussion guide.

THE DAY BEFORE

1. If there is a contact person with whom you've been working call him or her in order to touch base and be sure that they are expecting you and don't have any last minute concerns.

2. Prepare the box of focus group materials (see checklist at the end of this section). Make sure that you have plenty of forms and other supplies.

3. Get a cooler to keep ice in for the drinks (you'll have to borrow this from someone).

4. Get tape player from Linda.

THE DAY OF THE FOCUS GROUP

1. Pick up the checks for payment of the women.

2. Pick up party tray or other refreshments from your local supermarket. If you need additional supplies (such as napkins, drinks, bread, mayonnaise, mustard, etc.) then get those from the market as well.

3. Get a bag of ice to keep the drinks cold.

AT THE FOCUS GROUP

1. Arrange the room with chairs in a circle or other comfortable, non-hierarchical way. The notetaker's chair should be slightly to one side, near the group leader and right beside the tape recorder and box of materials.

2. Set up the tape recorder and test it. Before people arrive record a tag onto the tape. State your name, the date, the number of the focus group, and the location. Set the microphone so that it faces the group. Write the focus group number and date on the first cassette.

3. Arrange the food and refreshments. It is up to you whether you want people to eat as they come in or wait until after the group. I would expect that you would want to offer them drinks as they arrive.

4. It is best to wait until everyone is seated and ready and then to explain the focus group and then pass out consent forms. Refer to the training materials for more information on this. The tape recorder should be turned on as soon as everyone is seated and ready to begin. Remember, tape is cheap.

5. At the conclusion of the session remember to pass out the "Participant information forms" as well as the small "name and address forms" for those who might want to become involved with BCSP.

6. Answer any questions that participants raised during the session that you did not want to address during the focus group.

7. After everyone is finished eating and the focus group is really over give away any perishable food to participants. Pack up other supplies and materials.

AFTER THE FOCUS GROUP

1. After the focus group is over the leader and the notetaker will want to "debrief" and discuss the focus group. This discussion will be the basis for your field notes. You should tape it on a separate tape.

2. Turn in the receipt from supermarket to Mary Altpeter.

3. Return roster of check payments to Mary Altpeter.

4. Call or write the contact person or organization to thank them for their cooperation.

5. Restock the focus group box with supplies so that it will be ready for the next time.

6. Return tape player to Linda.

7. Return unused checks to Linda.

CHECKLIST OF MATERIALS TO BRING TO FOCUS GROUPS

Most of these materials should be kept together in a cardboard box which can simply be taken to the focus groups.

For Recording

Tape recorder, microphone, and stand
at least 4 full size cassettes for each focus group
extension cord

For the participants

Consent forms (plus 5 extras)
Participant information sheets
Participant name and address sheets
At least ten pencils for participants to use

For the Notetaker

Extra legal pads
Extra writing utensils

For Payment

Checks
Check roster

MODERATOR'S GUIDE FOR NC-BCSP FOCUS GROUPS

INTRODUCTION (15 minutes)

Hello and welcome to our session. Thank you for taking time to join us today.

We will be talking with you today about issues related to women's health in general.

> We are interested in learning from you about your experiences and about what you think.

Please feel free to share your ideas and opinions even if they are different from others.

> There are no right or wrong answers.
>
> We want to get as many different points of view as we can.

Anything we say here today is confidential and individual names or answers will not be shared with anyone.

> We also hope that you do not share with others outside the group what someone else says in our discussion today.

This session should last between 1 and 1 1/2 hours.

If there are no objections we will be tape recording this discussion to make sure we don't miss any of your comments.

> We will also be taking notes but often they are not as complete as when we tape record the discussion.

Try to speak up so the tape recording picks up your answers.

Since this is a group discussion you do not have to wait for me to call on you to speak.

Let's start by going around the room one at a time and introducing ourselves, and tell us (anything you would like about yourself). I'd like each of you to take about a minute to do this.

Social Support (10 minutes)

Who do you turn to when you have questions about women's health issues?

Who would you listen to in your family concerning women's health issues?

Who are the people in the community you can turn to for help (with a health problem) when you need it?

Breast Cancer (15 minutes)

Is breast cancer something that you personally worry about?

Who do you think gets breast cancer?

PROBE: age, family history.

What is the best way to find breast cancer?

PROBE: Have you heard about mammography?

Breast Cancer Screening (20 minutes)

How often should women have a mammogram?

PROBE: Women over age 50.

How old should women be when they start having a mammogram?

What are some of women's fears about having a mammogram?

PROBE: loosing breast, radiation, pain.

What are some of the reasons why a woman wouldn't have a mammogram?

PROBE: pain, cost, radiation.

Who would you listen to if they told you to have or not to have a mammogram?

Have any of you had a mammogram?

Where did you go for the mammogram?

What was it like to have a mammogram?

Would you have another mammogram?

Medical Persons (5 minutes)

Has a doctor ever discussed mammography with you?

PROBE: What did he or she say?

Has a doctor ever suggested that you have a mammogram?

Have you asked your doctor about getting a mammogram?

Health Department (10 minutes)

What kind of place is the _____County Health Department?

Is the ____County Health Department a place where older women could go if they needed to go for services to protect their health (e.g., breast exam, B/P check, immunization)?

Why? Why not?

Have you ever used any of the services of the health department?

Which services have you used?

What are other places locally for older women to go for services to protect their health?

What are some of the community groups that women belong to?

PROBE: Women over 50?

FOCUS GROUP MEMBER PROFILE

NAME _____

What is your age? _____

How long have you been a resident of Washington county? _____Years

Have you ever lived outside Washington county? _____Yes _____No

If YES: Where? _____

For how long? _____Years

What is the highest grade you completed in school? _____

Are you employed? _____Yes _____No

IF EMPLOYED: What kind of work do you do?

_____

When was the last time you had a mammogram?

_____ never had one

_____ 3 years or more ago

_____ within the last 2 years

Did you know anyone in the focus group before today?

_____ Yes _____ No

May we contact you again when we start a program on breast cancer in Washington county?

_____ Yes _____ No

IF YES: Address _____
Phone number (home)_____
(work)_____

FOCUS GROUP MEMBER PROFILE

NAME _____

What is your age? _____

How long have you been a resident of Bertie county? _____Years

Have you ever lived outside Bertie county? _____Yes _____No

If YES: Where? _____

For how long? _____Years

What is the highest grade you completed in school? _____

Are you employed? _____Yes _____No

IF EMPLOYED: What kind of work do you do?

_____

When was the last time you had a mammogram?

_____ never had one

_____ 3 years or more ago

_____ within the last 2 years

Did you know anyone in the focus group before today?

_____ Yes _____ No

May we contact you again when we start a program on breast cancer in Bertie county?

_____ Yes _____ No

IF YES: Address _____
Phone number (home)_____
(work)_____

FOCUS GROUP MEMBER PROFILE

NAME _____

What is your age? _____

How long have you been a resident of Tyrrel county? _____Years

Have you ever lived outside Tyrrel county? _____Yes _____No

If YES: Where? _____

For how long? _____Years

What is the highest grade you completed in school? _____

Are you employed? _____Yes _____No

IF EMPLOYED: What kind of work do you do?

_____

When was the last time you had a mammogram?

_____ never had one

_____ 3 years or more ago

_____ within the last 2 years

Did you know anyone in the focus group before today?

_____ Yes _____ No

May we contact you again when we start a program on breast cancer in Tyrrel county?

_____ Yes _____ No

IF YES: Address _____
Phone number (home)_____
(work)_____

FOCUS GROUP MEMBER PROFILE

NAME _____

What is your age? _____

How long have you been a resident of Martin county? _____Years

Have you ever lived outside Martin county? _____Yes _____No

If YES: Where? _____

For how long? _____Years

What is the highest grade you completed in school? _____

Are you employed? _____Yes _____No

IF EMPLOYED: What kind of work do you do?

_____

When was the last time you had a mammogram?

_____ never had one

_____ 3 years or more ago

_____ within the last 2 years

Did you know anyone in the focus group before today?

_____ Yes _____ No

May we contact you again when we start a program on breast cancer in Martin county?

_____ Yes _____ No

IF YES: Address _____
Phone number (home)_____
(work)_____

FOCUS GROUP MEMBER PROFILE

NAME _____

What is your age? _____

How long have you been a resident of Beaufort county? _____Years

Have you ever lived outside Beaufort county? _____Yes _____No

If YES: Where? _____

For how long? _____Years

What is the highest grade you completed in school? _____

Are you employed? _____Yes _____No

IF EMPLOYED: What kind of work do you do?

_____

When was the last time you had a mammogram?

_____ never had one

_____ 3 years or more ago

_____ within the last 2 years

Did you know anyone in the focus group before today?

_____ Yes _____ No

May we contact you again when we start a program on breast cancer in Beaufort county?

_____ Yes _____ No

IF YES: Address _____
Phone number (home)_____
(work)_____

CHAPTER 4

LAY HEALTH ADVISORS

An important part of your job as a health educator will be to recruit and train "Lay Health Advisors" to serve in the communities of your county. The following is an overview of the Lay Health Advisor model on which the outreach component of the North Carolina BCSP is based.

In every community there exisits a capacity for self-help. This capacity is embodied in part in a group of persons known to their neighbors to be reliable sources of advice, help, and leadership. When serving in the role of a LAY HEALTH ADVISOR, these natural helpers use their neighbohood, church and work-related networks to provide counseling and sound, basic ADVICE. They provide ASSISTANCE and referrals to appropriate community services. And when a neighborhood or community-wide health issue is encountered, they work with local groups and agencies to organize community ACTION efforts to address these problems.

It will be your job to identify the "natural helpers" in the communities of your county. In turn, these women will be able to reach the older African American women in their communities through existing kin, friendship, and job networks. It will be the job of the Lay Health Advisors to reach individuals and provide one on one assistance in getting mammograms. In addition, the Lay Health Advisors, with you as their leader, will work as a group to organize breast cancer control activities in community based organizations, such as churches.

The following is a list of questions and answers you may have about Lay Health Advisors. The information should help you get started in the process of identifying, recruiting and working with the women in your county.

1. What are Lay Health Advisors?

Lay Health Advisors are lay people in the community to whom others naturally turn for advice, emothional support, and aid. They provide informal spontaneous assistance which is so much a part of every day life that its value is often not recognized.

BCSP is aware of the value of these lay people and we are interested in building upon the natural support system within a community.

2. Where will I recruit the Lay Health Advisors from?

Chapter 3 described Focus Groups. In the series of focus groups that you will conduct you will begin to identify women in the community who are natural helpers and leaders. Once you have identified these women, you will want to send out a letter inviting those women to be Lay Health Advisors for BCSP.

3. How do I identify the "Natural Helpers" in a community?

When identifying Lay Health advisors in your community you will want to look for "natural helpers". "Natural Helpers" have certain qualities that make them stand out in the community. For example, you will want to look for people who easily articulate their opinions and encourage others to share theirs. During times of need, certain people in a community are turned to for care, advice, information, and support, it is these people whom you will want for the Lay Health Advisors in your counties.

4. What is the role of the Lay Health Advisors in BCSP?

Advise. The counseling the Lay Health Advisors provide is an extension of the natural exchange of advice and feedback given to the people who know and trust them.

Assist. The Lay Health Advisors assist the women in their communities by providing referrals to appropriate community services. They can play an important role in linking the overlapping networks in a community to provide a broader support system.

Action. The Lay Health Advisors can mobilize residents to undertake community-based responses to the identified needs in a community. In turn this collective political power can be used to negotiate and mediate with agencies for more and better resources.

5. How can the Lay Health Advisors change agencies and organizations within their communities?

The Lay Health Advisor can increase the social interaction between the agencies and their clients social networks. For example, if the local health clinic is under-used by African American women in a community, the Lay Health Advisor can identify why that is. As a result, she can negotiate with you as the health educator to work with the clinic to chage those factors that lead to a decrease in use.

BREAST CANCER

GET A MAMMOGRAM

NAME

WASHINGTON COUNTY LAY HEALTH ADVISOR TRAINING

ST. MARY'S CHURCH OF CHRIST
CRESWELL, NORTH CAROLINA

Monday, April 24, 1995	Monday, May 1, 1995
9:00 - 9:55 **"What is Breast Cancer?"** Linda Mayne, RN Regional Coordinator NC-BCSP	9:00 - 9:55 **"How to Lead a Discussion"** Georgia O'Pharrow Community Outreach Specialist Beaufort County
9:55 - 10:00 Break	9:55 - 10:00 Break
10:00 - 12:00 **"What is a Mammogram?"** Marlene James, RN Nursing Supervisor, M-T-W Health District **"Barriers to Mammography"** Nancy House, RN Adult Health Nurse, M-T-W Health District	10:00 - 10:55 **"InReach"** Ernestine Hassel, RN Public Health Nurse, M-T-W Health District 11:00 - 11:45 **"How the Health Care System Works"** Teresa McNair Washington County DSS
12:00 - 12:45 Lunch	11:45 - 12:30 Lunch
12:45 - 1:45 **"How to Give Advice and Assistance"** Eva Hill Community Outreach Specialist Martin County	12:30 - 1:30 **"The Mammography Experience"** Yvonne Cooper, Mammography Technician Washington County Hospital
1:45 - 2:45 **"How to Work as a Team"** Lucille Bazemore Community Outreach Specialist Bertie County	1:30 - 2:15 **"Finding Out What Works"** Judy Castro Graduate Student NC-BCSP
2:45 - 3:00 Questions and Wrap-Up	2:15 - 2:30 Break
	2:30 - 3:00 Graduation

BCSP-SOS Advisor Training Program

Washington County, North Carolina

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Schedule

Health Knowledge

- Breast Cancer: What is it?
  Who is at Risk

Stages of Breast Cancer

Breast Cancer Treatment

Barriers to Prevention and Treatment

HEALTH KNOWLEDGE

Breast Cancer: What is it?

Cancer is a group of diseases. More than 100 different types of cancer are known--and there are several types of breast cancer. They all have one thing in common: abnormal cell growth which destroys body tissue.

Healthy cells that make up the body's tissue grow, divide, and replace themselves in an orderly way all of our lives. This process keeps the body in good repair. Sometimes, however, some cells lose the ability to control their growth. They grow too rapidly and without any order. Too much tissue is made, and tumors are formed. **Tumors can be benign or malignant.**

Benign tumors are not cancer. Benign tumors are like warts. They do not spread to other parts of the body and are rarely a threat to life. Often benign tumors can be taken out by surgery, and they are very unlikely to return.

Malignant tumors are cancer. They can invade and destroy nearby healthy tissues and organs. Cancer cells can also break away from the tumor and enter the blood stream or lymph system. That is how cancer can spread to other parts of the body. This spread is called "metastasis." Even if cancer is removed from the breast, the disease sometimes returns because cancer cells have already spread.

Breast cancer is a **systemic** disease which means that over time it spreads throughout the body and is not just a disease of the breast alone. There is, however, a period of time of about 2 to 3 years when breast cancer is still **localized** in the breast; during that time, when the tumor is very small, it can often be detected by mammography.

HEALTH KNOWLEDGE

Breast Cancer: Who is at risk (Statistics)

In the United States

Cancer is the leading cause of death for women ages 35-74 in the United States.

- Breast cancer is the second leading cause of cancer deaths among women in the United States. (Lung cancer is the first.)
- Breast cancer is the leading cause of death in women ages 40-44.

It is estimated that in the United States in 1994 a total of 182,000 women will be diagnosed with breast cancer, and 46,000 will die of this disease.

In North Carolina

In North Carolina, it is estimated that in 1994 a total of 4,800 women will be diagnosed with breast cancer, and 1,200 will die of this disease.

In Washington County

In Washington County, in 1993, 5 women died of breast cancer; four were White and one was Black. In 1992, 12 women were diagnosed with breast cancer; 5 cases of breast cancer among White women and 7 cases among Black women.

For Black Women

- Breast cancer is <u>THE</u> leading cause of cancer death for Black women.

Rates for breast cancer are only slightly lower for Black women than White women, but Black women die from the disease at a higher rate. The relative five-year survival from breast cancer for White women is 78% and for Black women 64%. This higher mortality rate is because Black women are diagnosed at a later stage of disease than White women.

HEALTH KNOWLEDGE

Breast Cancer: Who is at Risk (Risk Factors)

There is a lot we don't know about breast cancer. We aren't sure what causes breast cancer. We only know who is at risk for it or, in other words, who most often gets breast cancer.

What We Know:

About 1 in 8 women will develop breast cancer some time in her life.

Breast cancer occurs before and after menopause.

- Breast cancer occurs more commonly after menopause.
- Environmental factors may play a more important role in breast cancer after menopause.
- Breast cancer before menopause is less common.
- Heredity may play a more important role in breast cancer before menopause.
  - The risk of getting breast cancer doubles for a woman whose mother or sister has had the disease.
  - If the mother had breast cancer before menopause her daughter's risk is somewhat higher.

There has been a lot of publicity about other factors that might be associated with breast cancer--such as a high fat diet, obesity, never having children, having the first child after the age of 30, having a late menopause--but we are still not sure about most of these.

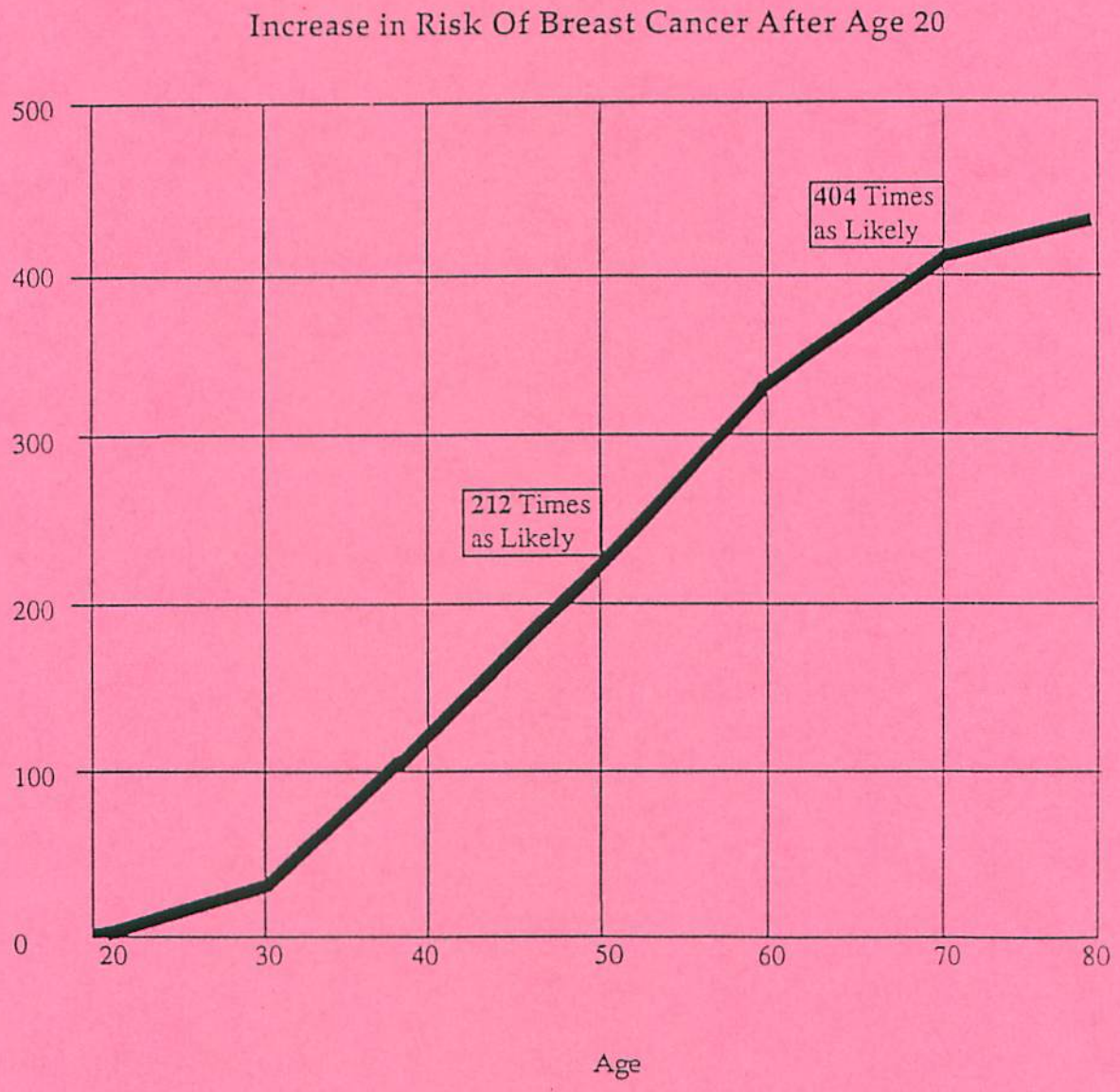
Age is the main risk factor for breast cancer. Women who are 50 and older have a higher chance of getting breast cancer, regardless of whether breast cancer is in their families.

- About 75% of all breast cancers are found in women over age 50.
- The disease is uncommon in women under the age of 35.

HEALTH KNOWLEDGE

Breast Cancer: Who is at Risk - Age

This chart shows that the relative risk (chance) of getting breast cancer increases as a woman gets older. For example, a woman who is age 50 has about 200 times the chance of getting breast cancer as a woman who is 20 years old.



HEALTH KNOWLEDGE

Breast Cancer: Survival

Survival from breast cancer depends on how early the disease is discovered (how much it has spread or what stage it is in).

The Stages of Breast Cancer

Carcinoma in situ is very early breast cancer. The cancer is found in a local area and in only a few layers of cells.

Stage I tumor is one that is bigger than 2 centimeters (about an inch) and has not spread beyond the breast.

Stage II tumor is from 2 to 5 centimeters (about 1 to 2 inches) and/or has spread to the lymph nodes under the arm.

Stage III tumor is larger then 5 centimeters (about 2 inches) and involves more of the underarm lymph nodes and/or has spread to other lymph nodes or other tissue near the breast.

Chances for Survival

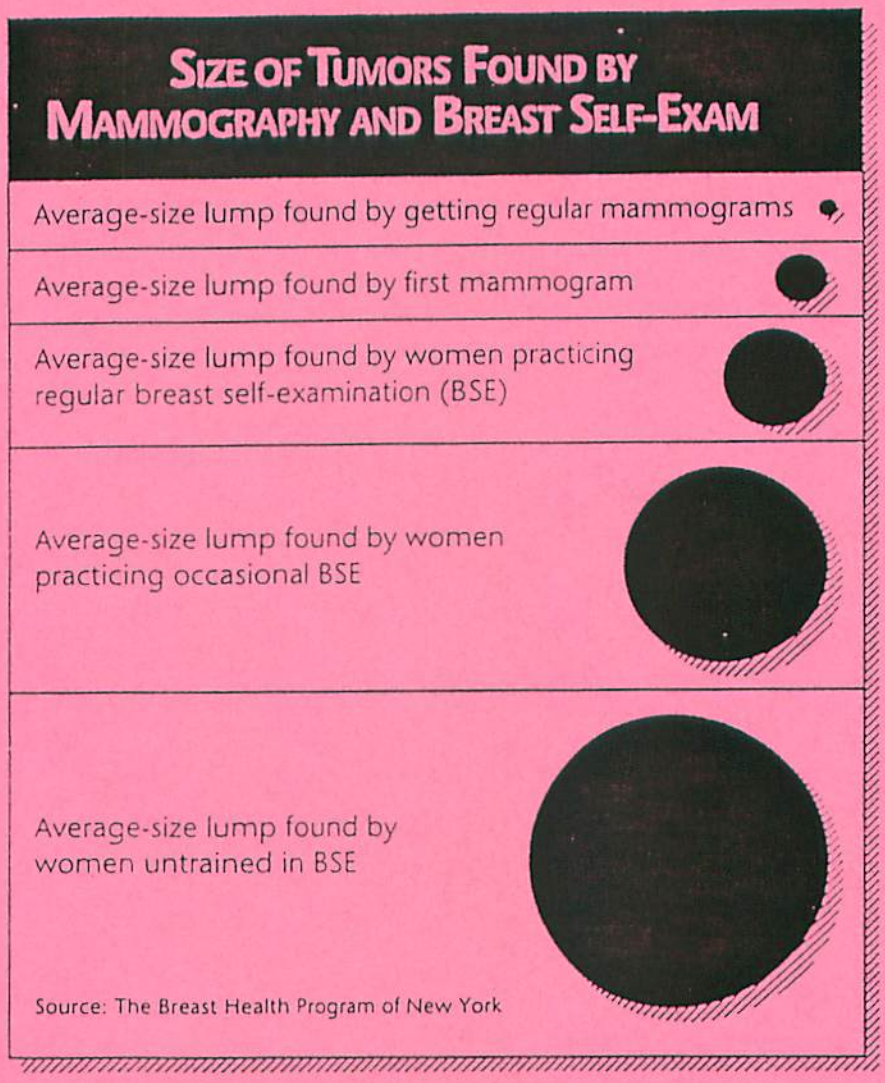
People survive breast cancer best when tumors are small and no lymph nodes are involved. 95% of women survive 10 years or longer when breast cancer is found when the lump is too small for a woman to feel it herself but when it can still be found by a mammogram.

When the cancer has spread to the lymph nodes (late stage) only 50% of the women with cancer live 10 years or longer the survival drops to 50% or less. In the US Today, unfortunately, most breast cancer is found at this later stage, rather than earlier.

The size of breast cancer lumps found by breast self-exam averages 2.5 centimeters (one inch). Mammograms can find breast lumps the size of a pin head

We know that breast cancer death rates could be reduced by 30% if more women over 50 got regular mammograms like the NCI believes they should.

Size of Tumors Found by Mammography and Breast Self-Exam



HEALTH KNOWLEDGE

Stages of Breast Cancer

	Very Early	Early	Late
Signs	Lump that can't be felt	Lump you can feel but small	Lump that breaks off and travels
Detection	Mammogram	Breast self-exam Mammogram Clinical breast exam Breast biopsy (possibly)	Breast self-exam Mammogram Clinical breast exam Breast biopsy
Treatment	Lumpectomy	Lumpectomy Mastectomy Radiation * Chemotherapy *	Mastectomy Radiation * Chemotherapy *
How many women alive after 10 years	95%		50%

---

* May be used together with lumpectomy or mastectomy

HEALTH KNOWLEDGE

Breast Cancer: Treatment

Early Detection

Finding breast cancer at an early stage is important because the success of treatment depends on how early breast cancer is found.

Early detection means less extensive surgery is possible; sometimes when the lump is small, the breast itself can be saved and just the cancer taken out.

Treatment Choices

A woman diagnosed with breast cancer has several treatments she can choose from, depending on how advanced her cancer is.

Women should know about these choices and they should be encouraged to get at least two doctors' opinions before making any decisions about the type of treatment they will get.

The treatment choices are:

❶ Lumpectomy which removes only the breast lump and maybe a few lymph nodes under the arm;

❷ Mastectomy, which removes the breast and the lymph nodes under the arm;

❸ Radiation and/or chemotherapy, which are used in combination with lumpectomy or mastectomy.

Radiation therapy uses high-powered rays to stop cancer cells from growing. Like surgery, radiation therapy is a local treatment; it affects only the cells in the treated area. Usually treatments are given 5 days a week for 5 to 6 weeks.

Chemotherapy uses drugs to kill cancer cells. One drug or a combination of drugs may be used. The drugs enter the blood stream and travel through the body. Chemotherapy is given in cycles: one treatment period followed by a rest period, then another treatment period and so on. This is called "systemic" therapy.

HEALTH KNOWLEDGE

Barriers to Prevention and Treatment

Group interviews conducted with Black women in Washington County showed that there are many reasons why women delay in getting a mammogram:

- Women are afraid that they might find cancer if they get a mammogram-- they think that getting a mammogram is just "looking for trouble."
- Women believe that if breast cancer is meant to happen, it will happen -- so they don't see any reason to worry about it ahead of time.
- Women incorrectly believe that if they examine their own breasts, they don't need to get a mammogram unless they find a knot or lump.
- Women don't always understand why they should get a mammogram or what the benefits of getting one are.
- Women have fears about the mammogram procedure:
  -- women are afraid that the mammogram will hurt;
  -- women are afraid that the technician will be too rough;
  -- women wrongly believe that mashing or radiation from the machine will cause cancer.
- Women have fears about what will happen if they have breast cancer, including:
  -- the fear of losing a breast and becoming "less of a woman";
  -- the fear of being "cut up";
  -- fears that they will have to take treatments (e.g., radiation, chemotherapy) that will make them sick.
- Some women don't feel that they can afford a mammogram.
- People feel uncomfortable talking about cancer, in general, and women who have breast cancer often don't tell anyone about it.
- Some women don't talk to other people, even their families, about their health concerns.

BCSP-SOS Advisor Training Program

Washington County, North Carolina

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Schedule

Health Knowledge

- What is a Mammogram?

  How a Mammogram Differs from a Breast Self-Exam and a Clinical Breast Exam

  Mammogram Screening Guidelines

HEALTH KNOWLEDGE

What is a mammogram?

Description

A mammogram is a breast X-ray. The X-ray is studied carefully by a trained technologist who looks for any problems. A breast problem could be breast cancer, or it could be some other, often harmless, condition. A mammogram is the best way to find breast cancer early. The earlier breast cancer is found, the better the success of treatment and the higher a woman's chances to live a long life.

There are two types of mammograms:

1. **Screening mammograms test healthy women who have no symptoms;**
2. **Diagnostic mammograms evaluate the breast tissue of women who have problems like breast lumps, nipple discharge, or breast pain.**

Discussion

Read the article on the following page. If you've had a mammogram, think about how your experience was different or similar to the procedure described there.

Use the following questions to guide your discussion:

- How was your experience different from the one described? How was it the same?
- Did you feel your privacy was respected as much as possible during the mammogram? Was the technologist male or female? Does it matter?
- Was the procedure uncomfortable or painful?
- How many X-rays did they take of each of your breasts?

A simple procedure

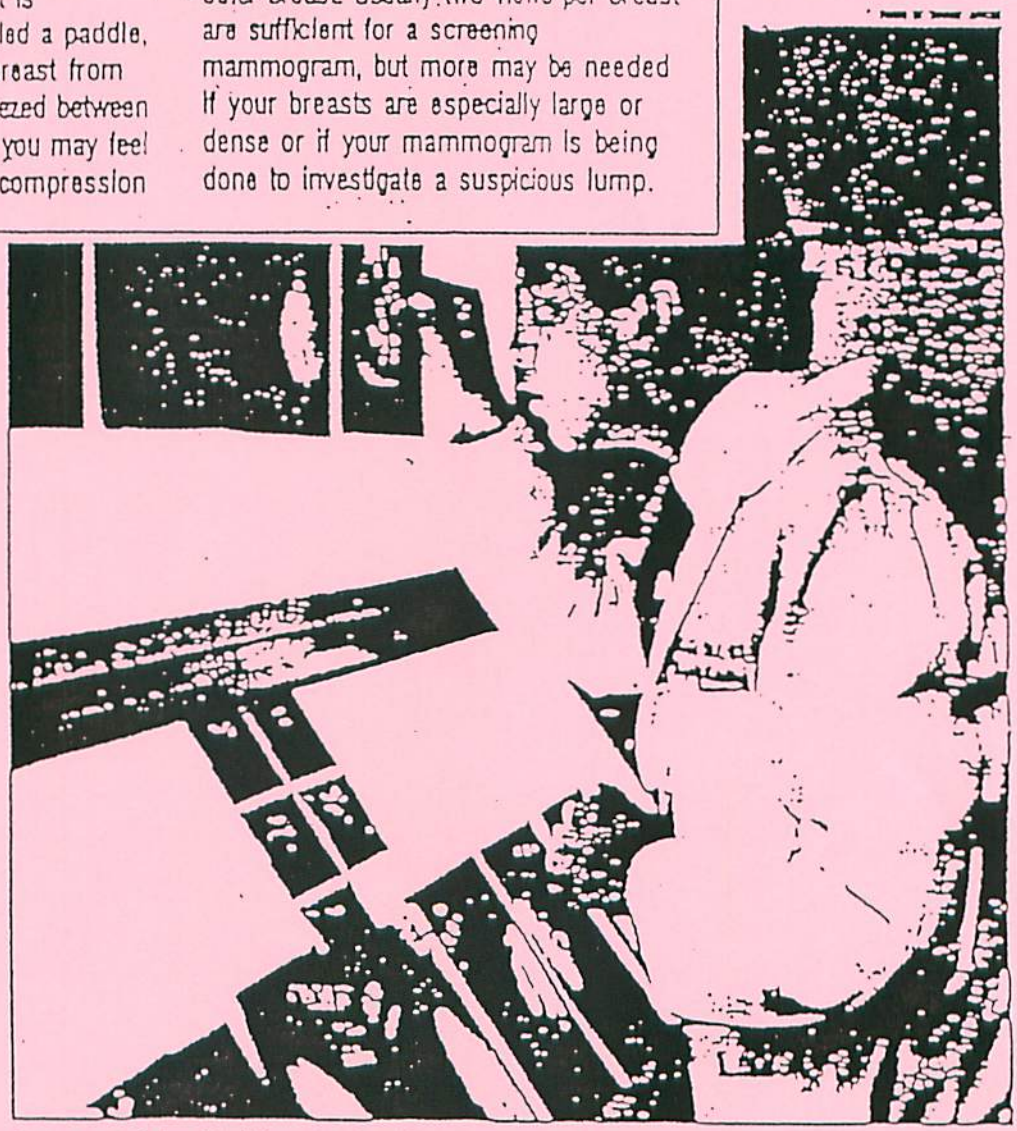
And it takes up very little time

When you go for a mammogram, you are taken to a private room and asked to undress from the waist up. The nurse gives you a front-opening jacket to wear and has you stand in front of a large X-ray machine.

The technologist—usually, but not always, female—positions one breast on a small platform. The breast is compressed by a device called a paddle, which is lowered onto the breast from above. With your breast squeezed between the platform and the paddle, you may feel discomfort or pain, but the compression is important for the picture to be clear.

Then you hold your breath, the X-ray picture is snapped and the paddle is immediately released.

The breast is then repositioned slightly to get an all-around view, the paddle is lowered, and another picture is taken. Then the procedure is repeated on the other breast. Usually two views per breast are sufficient for a screening mammogram, but more may be needed if your breasts are especially large or dense or if your mammogram is being done to investigate a suspicious lump.



Doctor at Columbia Hospital for Women in Washington, D.C., reviews results of a mammography. The entire procedure generally takes no more than ten minutes.

HEALTH KNOWLEDGE

How Mammogram Differs from Breast Self-exam and Clinical Exam

For many years now, women have been advised to check their breasts monthly. The goal of these breast self-exams is to notice any changes in the breasts that may show that something is wrong. Like mammograms, breast self-exams are supposed to find cancer in its early stages.

Many women who regularly check their breasts think they don't need to have annual mammograms. They think: "Why spend the time and money for a mammogram that may be uncomfortable and embarrassing when I can get the same results in the privacy and comfort of my own home?" Breast exams by doctors or nurse practitioners are often thought of in the same way: "Wouldn't my doctor/nurse know my body better than a strange technician and find something just as easily?"

This kind of thinking can be dangerous. The important difference between a mammogram and clinical or self breast self exam is earlier detection.

- A mammogram can find a lump two years before it can be felt by the woman or her doctor.
- A mammogram can find a change in the breast before a woman has any symptoms.

Finding a breast lump early is the single most important way to do successful breast cancer treatment and lead a long life free from breast cancer. The earlier a breast cancer lump is found, the easier it is to treat and the more treatment choices women have.

- A woman whose breast cancer is found by a mammogram has nearly twice the chance of living a long time than a woman whose breast cancer is found by a breast exam.
- Cancer treatment today is less disfiguring and less scary than it used to be. Removing the whole breast isn't always necessary and surviving until old age after treatment is much more likely.

HEALTH KNOWLEDGE

Mammogram Screening Guidelines

National Cancer Institute (NCI)
Guidelines for Mammography Screening
for Women Who Do NOT Have Breast Symptoms

Women 40 years of age or younger:

Breast self-exam every month
Clinical breast exam at least every 3 years

Women between 40 and 49 years of age:

Breast self-exam every month
Clinical breast examination every year
Women who are at high risk for breast cancer may need a mammogram
Women under 50 should talk to a health care provider about their need for a mammogram

Women age 50 and over:

Breast self-exam every month
Clinical breast examination every year
Mammograms every 1 to 2 years

As an SOS Lay Health Advisor, you must recognize that many women do not know the difference between a mammogram, a breast self-exam, and a clinical breast exam. Every woman needs to know the NCI mammography guidelines described above. Older women who are health conscious and check their own breasts regularly should be told that breast self-examination is not enough; they also need to get mammograms every year.

BCSP-SOS Advisor Training Program

Washington County, North Carolina

SAVE OUR S.O.S. SISTERS FOR PEACE OF MIND

Schedule

Health Knowledge

- Barriers to Mammography

  Women's Opinions about the Health Care System: Barriers and Benefits

HEALTH KNOWLEDGE

Barriers to Mammography

In 1990, approximately 58% of Black women 40 and older had ever had a screening mammogram while 65% of White women in that age group had had one. [Behavioral Risk Factor Surveillance System, 1990]

Common Concerns About Breast Cancer and Mammography

Concerns	Responses
I think that women who don't breastfeed, or who take pills to stop the breastmilk, are more likely to get breast cancer.	Scientists are still not sure about this. It seems that breastfeeding for at least one whole year might reduce a woman's chances of getting breast cancer. Still, there are women who did this, but have breast cancer. So, breastfeeding is no guaranteed way for women to avoid breast cancer.
I believe that bruising the breast can cause breast cancer.	Bruises are the result of internal bleeding. After a bruise goes away, it doesn't have any long-term effects. Bruises do not cause breast cancer, or any other kind of cancer.
If breast cancer is meant to happen, it will happen, so why should I worry about it?	Survival from breast cancer depends on how early the disease is discovered. 95% of women survive 10 years or longer when breast cancer is found early.
The mammogram will hurt.	Because the technician squeezes the breast to get a clear image, a mammogram may be a little uncomfortable. For women with very sensitive breasts it may even hurt. Each X-ray takes only seconds. The discomfort is bearable and short. (Many women will say it hurt but not enough to keep them from getting another one.)
I'm afraid the bruising from the mammogram will damage my breasts or give me cancer.	The mammogram procedure does not cause cancer. The technician has to squeeze the breasts to get a good picture, but this does not cause bruising.
The radiation from the mammogram might give me cancer.	Today's machines release much less radiation than the first X-ray machines. Today, there is less radiation exposure from a mammogram than from an airplane ride. The benefits of early detection far outweigh the risks of X-ray exposure.

HEALTH KNOWLEDGE

Barriers to Mammography

Common Concerns About Breast Cancer and Mammography (continued)

Concerns	Responses
Some mammogram technicians screw the machine down too hard.	X-ray technicians who do mammograms have gotten special training to be able to do breast X-rays. Sometimes the technician has to try many positions to be able to see all parts of the breast. Women should ask their technicians to explain what they're doing, and should tell the technician if it hurts.
I don't need to get a mammogram if I examine my own breasts and feel for knots or lumps.	Breast self-exam isn't enough. A mammogram can find a knot or lump when it is very, very small (the size of the head of a pin). Women have a much better chance of surviving when breast cancer is found early on. Mammograms are the best way to find cancer early.
I'm afraid the mammogram will find cancer.	Most lumps found by a mammogram are not cancer. But, the mammogram tells your doctor to look more closely if a lump or growth exists. It's better to have a lump turn out to be nothing than to allow a cancer to grow undetected. A mammogram is the best way to detect cancer early.
I'm afraid that I will lose a breast if they find breast cancer.	Treatment for breast cancer has changed a lot over the last ten years. If they are caught early enough, not all breast cancers require the breast to be removed.
If they find breast cancer, I'm afraid I'll have to take treatments that will make me feel sick.	Some of the treatments can, but don't always, make you feel sick. It depends on how much you need. A doctor can always give medicine for side effects, like feeling sick, when the woman asks for it.
My doctor has never told me to take a mammogram.	When a woman goes to see her doctor, it is usually for a specific problem and the doctor may not think to discuss mammography. So, if a woman's doctor doesn't bring it up, the woman should ask the doctor herself.

HEALTH KNOWLEDGE

Barriers to Mammography

Common Concerns About Breast Cancer and Mammography (continued)

Concerns	Responses
My doctor just told me to get a mammogram, but didn't explain why or what it's like.	Women often have questions about mammography. Doctors, SOS advisors, or the 1-800-4CANCER line can help answer questions that women have.
I get confused by the words "mammogram" and "mammography."	"Mammogram" and "mammography" mean the same thing.
Mammograms cost too much.	If you have health insurance, it will pay for a mammogram once a year. If you're over 65 years old and are paying $41 a month for Medicare, it will pay for your mammogram every other year. There is also a special program at the health department that will pay for the mammogram, insurance deductible, or Medicare co-payment for women who can't afford these costs.

HEALTH KNOWLEDGE

Women's Opinions about the Health Care System: Barriers and Benefits

The women who were interviewed also mentioned some <u>good things</u> about the health care system in Washington County:

- Doctors and health department nurses are a good source of information when women have questions about their health.
- Some women like going to the health department because it doesn't cost a lot, and it has many of the services older women need (e.g., yearly check-ups, pap smears, blood pressure checks, sugar tests, cholesterol checks, flu shots).
- When doctors strongly recommend getting a mammogram, women listen to their advice.
- Some mammogram technicians are gentle and explain what they are going to do, and then women aren't as scared or uncomfortable.

HEALTH KNOWLEDGE

Women's Opinions about the Health Care System: Barriers and Benefits

Exercise 1

Take each barrier concerning the health care system and explain what you would say to a woman who says something like it.

The group interviews in WashingtonCounty described the following health service barriers:

- Except for private doctors and the health department, there aren't a lot of places where older women can get health care.
- If women have a family doctor, they don't see any reason to go to the local health department.
- Some women think the health department is mostly for pregnant women or mothers of small children -- they don't know that it's also a place where older women can get services.
- Some doctors forget to discuss mammograms, or don't clearly tell women they should get one.
- Even when doctors tell women to get a mammogram, they don't always go into muc detail about why women need one, or what the mammogram will be like.
- Some women don't fully trust their doctor's advice about getting a mammogram, but others want the opinion of a second doctor before they will get one.
- Women who get mammograms have different experiences, depending on the person giving the mammogram -- women say that some mammogram technicians are too rough.
- Women believe that mammograms are too expensive, especially for women who don't have health insurance.

BCSP-SOS Advisor Training Program

Washington County, North Carolina

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Schedule

Health Knowledge

- The Mammogram Experience

HEALTH KNOWLEDGE

The Mammogram Experience

There are many steps to getting a screening mammogram. This session will look at what those steps are and address some of the barriers a woman might face at different steps. We will look at what a woman needs to know to make the best, most informed choices for herself.

We will discuss the following steps for a screening mammogram.

- Remembering to get a mammogram next year
- Making an appointment
- Getting to the radiology (mammography) center
- Mammography centers in the area
- Filling out forms
- Getting the mammogram
- Getting the results from the mammogram
- Paying for the mammogram

First, here are some definitions.

A **radiologist** is a medical doctor who is specially trained to read X-rays.

A **technologist** is a licensed specialist trained to assist women getting mammograms who runs the mammography machine that makes the mammogram.

A **mammography machine** is an X-ray machine specially designed for taking breast X-rays.

An **accredited radiology center** is a center that has been investigated by the American College of Radiology (ACR) and has met their standards. Before a mammogram center is accredited by the ACR, it must meet the following requirements:

- The radiologists must be specially trained in reading mammograms.
- The technologists must be properly licensed.
- The equipment must be specially designed for mammography.
- Only mammograms can de done on that machine and a certain number have to be done a week.

HEALTH KNOWLEDGE

The Mammogram Experience

Remembering to Get a Mammogram Next Year

It's important for a woman over 50 to remember to get a mammogram every year. Some ways she might remember:

Go with a friend each year, to help remind each other;
make it a yearly lunch date.
Record the date on her calendar for the next year.
Go on her birthday or another special day.

Spend some time brainstorming with the woman about how she can remind herself to get a mammogram.

Making an Appointment

Many radiology centers require that a woman get a referral from her doctor before she can make an appointment for a mammogram. In this case, the woman would need to ask her doctor:

- Will you refer me to a radiology center?
- Is the center accredited?

Some radiology centers accept "walk-in" patients and will make an appointment without a doctor's referral. Sometimes these centers require that the patient give the name of a doctor to whom the results can be sent. Other times they supply a list of doctors from whom the patient can choose to have the results sent.

Before making an appointment for a mammogram, the woman should ask the radiology center:

- Do you use machines specifically made for mammography?
- Is the person who does the mammogram a registered technologist?
- Is the radiologist specially trained to read mammograms?
- Does your center do at least 10 mammograms per week?
- Is the mammography machine calibrated (checked over) at least once a year?

If the center can not answer "yes" to all of these questions, find another center.

HEALTH KNOWLEDGE

The Mammogram Experience

Getting to the Radiology Center

Of course, a woman can arrive at the center by herself. The mammogram will not affect the woman's ability to drive herself home, but she may want to bring someone along for emotional support if she's worried about the experience.

Health care providers in the area are aware of the need for help with transportation in this area; they are trying to work out a solution to the problem. For current information about transportation, contact the Martin County Health Department.

Filling Out Forms

When a woman gets to the mammography center she will probably have to fill out some forms. This can be made easier if she brings the following things with her:

- Insurance policy and forms
- Medicare or Medicaid card and identification number
- Name and phone number of doctor who will receive the mammogram report
- A friend; if the woman has a low reading level, she may want to bring a friend to help read the forms.

HEALTH KNOWLEDGE

The Mammogram Experience

Getting the Mammogram

We discussed the details of what happens when a woman arrives at the radiology center for her mammogram. Now, we would like to discuss some of the things a woman may want to do to prepare for the day of the appointment.

When a woman goes in for a mammogram, it's a good idea for her to wear clothes that she can get in and out of easily. A 2-piece outfit usually works better than a dress. She should not put on perfume, deodorant, powder, or jewelry that day.

Some women prefer to go in for the appointment on their own while others prefer to take a friend. The decision is one to be made by each woman, but it's a good idea for the woman to think about it before the day of the appointment arrives.

Here are some questions the woman may want to ask the technologist:

- Is there anything I should do to get ready for my mammogram?
- What will the mammogram show?
- Who gets the report of my mammogram?
- Can it also be sent to the doctors who treat me? To the Washington County Health Department?
- How long will it take before I hear about the results of the mammography report?
- How will I find out the results? Should I call you or my doctor?
- Will you call me if something is wrong?

HEALTH KNOWLEDGE

The Mammogram Experience (continued)

Getting the Results from the Mammogram

A woman usually receives the mammogram results from her doctor. Most mammograms are normal -- showing no abnormal growths that could indicate a problem. But, some mammograms show abnormal growths that call for further investigation. Most abnormalities or lumps found by a mammogram are not cancer. If the mammogram report shows a problem, a biopsy is likely to be done. A biopsy is a simple procedure where a very small amount of breast tissue is removed to test it for cancerous cells. There are several types of biopsies. The type of biopsy the doctor chooses depends on the size and location of the lump and the general health of the woman.

Some types of biopsies:

fine needle aspiration -- a thin needle is used to collect a few cells. Fine needle aspiration is done in the doctor's office when the woman is completely awake.

core needle aspiration -- a slightly larger hollow needle is used to remove a small piece of tissue. Core needle aspiration is also done in the doctor's office when the woman is completely awake.

excisional biopsy -- if the lump is small (less than one inch) the entire lump may be removed for diagnosis. This is also called a **lumpectomy**. Excisional biopsy is done in the outpatient area of a hospital and the woman may be asleep or awake.

incisional biopsy -- removal of part of the lump. Incisional biopsy is done in the outpatient area of a hospital and the woman may be asleep or awake.

HEALTH KNOWLEDGE

The Mammogram Experience

Here are some questions that a woman referred for a biopsy can ask her doctor:

- What type of biopsy will I have? Why?
- Can the lump be drained with a needle?
- How long will the biopsy take?
- Will I be awake during the biopsy?
- Can it be done on an outpatient basis?
- Will the biopsy leave a scar?
- How soon will I know the results of the biopsy?
- If I do have cancer, what other tests should I have?
- After a biopsy, if cancer is found, how much time can I take to decide what type of treatment to have?

Today, most women who receive a biopsy result that is positive for cancer have some time after the biopsy to consider their treatment options. This is called a two-step procedure. Some doctors in some cases will do a one-step procedure where a biopsy and a mastectomy are performed at the same time. Therefore, it is important for a woman going in for a biopsy to ask the doctor what his or her practice is if cancer is found. And remember, if the doctor doesn't answer all the questions satisfactorily, you can, and should, ask another health care provider or call 1-800-4CANCER for more information.

BCSP-SOS Advisor Training Program

Washington County, North Carolina

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Schedule

Role of the SOS Advisor

- How to Give Advice and Assistance

  How to Listen and Be Listened To: Counseling Guidelines

  How to Use the Ask, Advise, Assist Method

  Counseling Techniques Exercise

  Role Play

- How to Use the BCSP-SOS Brochure

SOS ADVISOR ROLE

How to Listen and Be Listened To: Counseling Guidelines

As a Lay Health Advisor, you may know a lot about breast cancer and mammography, but it won't do any good if no one will listen to your advice. Here are a few tips on how to counsel effectively. Some of these suggestions you may already know, others may be new to you.

Counseling guidelines

- Be supportive and non-judgmental--nothing she says is bad or stupid.
- Ask open-ended questions that can't be answered with yes or no. Questions that begin with why, what, or how, for example, get fuller answers.
- Make sure the questions you ask are ones you can and would answer yourself. Don't ask questions that are too technical or too personal.
- If there is a disagreement, don't defend or argue. Ask more questions to get more information and check-out what she means. For example, "Why do you think that? Are you worried/afraid that...?"
- Because you are a Lay Health Advisor, she may want you to tell her what to do. Guide her, but make sure the decision made is hers.
- Retell her things she has said, especially if you are unsure about what she means or if she seems unsure herself. For example, "So you feel/think that..."

These guidelines help create a sense of trust and a positive tone in a counseling session. It is also important to direct the discussion in such a way that you know what kind of information and advice each woman needs.

SOS ADVISOR ROLE

How to Use the Ask, Advise, Assist Method

Here are some guidelines for directing your mammogram counseling:

ASK

- Has she ever had a mammogram? Does she see a doctor or nurse regularly and have her breasts examined at the visit?
- Find out what she knows about breast cancer. Does she worry about getting breast cancer?
- Find out how she feels about getting a mammogram.
  - If she's never had one, why not?
  - If she's had one, what was her experience like? Does she have any fears about the test (radiation, pain, cost)? Does she plan to have another one? If not, why not?

ADVISE

- Give her information about mammograms and breast cancer. Offer advice that fits her concerns about having one done.
  - If she's never had one, highlight the importance of mammography.
  - If she's had one but has no intentions of going again, lower the barriers she is facing.
  - If she's has one regularly, provide reinforcement.
- You may want to tell her about the risk factors for breast cancer. Let her know the screening guidelines. Describe how the test is performed. Let her ask questions.

ASSIST

- Find out if she knows what to do and where to go for the test. Give her a list of accredited facilities in the area. Tell her she can call 1-800-4CANCER to get information about cancer and radiology (mammography) centers.
- Find out if she thinks she will set up an appointment and if she needs help (transportation, money) to make it. Does she have friends or family members who can help? Does she qualify for assistance (Medicare or Medicaid)?
- Leave her with written information and, if you want, your phone number. Tell her you'll check back with her in a week. (When you check back, if she hasn't made the appointment or has missed it, find out why and help her solve the problem.)

SOS ADVISOR ROLE

How to Use the BCSP-SOS Brochure

The BCSP-SOS brochure for Martin County will help you use the Ask, Advise, Assist method. Take a moment and look over the brochure. Any ideas about the kinds of women that would learn the most from it?

This brochure has special messages and pictures for three kinds of women:

- those who have never had a mammogram;
- those who have had a mammogram but have no intentions of having another one and;
- those who have had a mammogram and continue to get them annually.

Show her the brochure and **ask** questions to figure out which of these three groups she falls into.

- When was the last time a doctor or nurse checked your breasts?
- When was the last time someone x-rayed your breasts?

SOS ADVISOR ROLE

How to Use the BCSP-SOS Brochure (continued)

After deciding which group a woman falls into, the Ask, Advise, Assist method helps you use the brochure to help them.

For a woman who says she never had a mammogram:

- Ask "Why not?"
- Ask "What have you heard about a mammogram?"
- Ask "Who can get breast cancer?"

Point to sections of the brochure.

- Advise her on who gets cancer, what a mammogram is, and who needs one.

Point to pictures of lump sizes.

- Advise her on the difference between the size of a lump that can be felt and a lump that can be found by a mammogram.
- Assist her by showing the list of places in the area where she can get a mammogram and their prices.
- Assist her by showing the NCI guidelines in the brochure.
- Assist by offering to help her get a mammogram.

For a woman who has had a mammogram but has no intentions of having another one:

- Ask "Why haven't you gone back?"

Point to the quotes in the brochure by women who overcame similar fears or problems.

- Advise her by sharing your own experiences with getting a mammogram or describing other women's stories in overcoming fears or problems.

Point to the picture of lumped sizes.

- Advise her on the difference between the size of a lump that can be felt and a lump that can be found by a mammogram.
- Assist her by showing the list of places in the area where she can get a mammogram and their prices.
- Assist her by showing the NCI guidelines in the brochure.
- Assist by offering to help her get a mammogram.

A woman who has regular mammograms should receive praise.

Reinforce her positive behavior. The portion of the brochure that lists all of the accredited radiology (mammography) centers in the area may be of interest to her.

SOS ADVISOR ROLE

Ask, Advise, Assist: A Summary

To review, discuss the different kinds of things to do using the Ask, Advise, Assist method just presented.

Keep in mind that a good counseling session will:

ASK

Figure out if she falls into the group of women who has:
❶ never had a mammogram;
❷ had one but does not intend to get another one;
❸ had one and gets a mammogram every year.
Then,
- get the facts
- find out/discuss feelings and give emotional support

ADVISE

- give facts/information from the BCSP-SOS brochure according to the groups she's in
- give appropriate feedback/advice

ASSIST

- help solve problems
- give assistance
- leave her the brochure with your name and phone number.

SOS ADVISOR ROLE

Counseling Techniques Exercise

As a whole group, think about questions or statements that could be useful to you in the future. Use the spaces below to write other questions or things to say down. For example, when trying to "Get the facts," what is something you'd ask or say?

Goals of Ask, Advise and Assist	Question or Statement to Use
ASK	
❶ Get the facts	Have you ever had a mammogram?
❷ Discuss feelings and give emotional support	How was it having a mammogram?
ADVISE	
❸ Give facts/information	Have a mammogram every year after you turn 50. A mammogram can show a lump two years before you or your doctor can feel it.
❹ Give appropriate feedback or advice	A mammogram does not hurt.
ASSIST	
❺ Help solve problems	Do you have a way to get to the clinic?
❻ Give assistance.	How can I help you get a mammogram?

SOS ADVISOR ROLE

Role Play

Pair up with a partner. Act out a counseling session. For Exercise 1, one of you will be the SOS Lay Health Advisor and the other is her friend being advised. Keep in mind the barriers to prevention and treatment (on page 13) we discussed in this session. Use the Ask, Advise, Assist method and the BCSP-SOS brochure to counsel your friend. Once you've finished Exercise 1, switch roles and try Exercise 2.

Exercise 1

Friend: You are a 55-year-old woman. You had your first mammogram when you were 50 because your doctor advised you to get one, but you've never had another one because it had hurt. Every two to three weeks you check your own breasts for lumps. Last week you found out that your neighbor was trained as an SOS Advisor. You go over to her house to congratulate her.

Exercise 2

Friend: You are a 72-year-old woman. You have never had a mammogram and you think the radiation from it is dangerous. You also believe that younger women are more likely to get breast cancer than women your age. You see the SOS Advisor at a church meeting and she approaches you about getting a mammogram.

BCSP-SOS Advisor Training Program

Washington County, North Carolina

Schedule

Role of the SOS Advisor

- Leading a Good Discussion

  Styles for Leading a Discussion

  Leading a Good Discussion: Exercises

- How to Lead a Discussion with Small Groups Using the Brochure

  Discussion with Small Groups Using the Brochure: A Leader's Guide

SOS ADVISOR ROLE

Leading a Good Discussion

Leading a good discussion with a group involves many of the same skills discussed in the session on how to give advice. Review the counseling guidelines and pointers for directing a counseling session (see: Counseling Guidelines located in the "How to Give Advice and Assistance section).

In a group discussion it is important to show that anything the group says will be listened to and not judged. It is also important to direct the discussion to focus on the topic of interest, in this case, mammography and breast cancer.

The **goals** of a good discussion are the same as for a good counseling session:

- Get the facts
- Discuss feelings and give emotional support
- Give facts/information from the BCSP-SOS brochure
- Help solve problems
- Guide decisions

In a group, these goals are reached in a somewhat different way, because everyone in the group works towards these goals. To have a good group discussion:

- ◆ Keep the discussion from being focused on you as the only source of information and emotional support. If you are asked a question about your experience or your opinion, encourage others to talk about some of their experiences or opinions before offering your own.
- ◆ Involve as many of the participants as possible. If you notice one person hasn't said much, ask her directly what her opinion or experience is as it relates to what is being discussed at that moment.
- ◆ Keep the discussion directed on the topic of interest. Let people talk, but if the subject gets too far from mammogram and breast cancer bring the focus back by asking a question or making a statement about the topic or by suggesting that they move on to the next item on the agenda.

SOS ADVISOR ROLE

Styles for Leading a Discussion

Everyone has her own style--even as a discussion leader. Which style is yours?

Participation

Recognizes the insights and leadership ability of each member of the group. Encourages quiet people to speak up, and ones who talk a lot to listen more to others.

Consensus

The discussion leader uses methods that allow people with many different perspectives on a situation to come to a unified decision or consensus. Emphasizes points of agreement and builds on them.

Responsibility

Understands her concern is for the whole group, rather than any individual or faction within the group. She exacts this responsibility by being prepared for the meeting. Keeps the group focused, on time, and moving toward a decision.

Co-learner

The discussion leader realizes that the only "right" decision is the one the group builds for itself. She does not picture herself as an "expert", but rather as a co-learner with the meeting participants.

Objective

The discussion leader is deeply engaged with the group, but remains open and objective about the issues. (A person with a high stake in the issues discussed will ask someone else to facilitate.)

Innovation

Encourages people to think of fresh solutions and new ideas that might help people break out of established ruts or patterns of response. She uses humor, affirmation, small groups and large groups to break tension and expand the imagination of the group.

Are you more than one style? Are some styles better than others? Why? Does it sometimes depend on the situation?

SOS ADVISOR ROLE

Leading a Good Discussion: Exercises

Exercise 1

Take a few minutes with the group at your table to discuss the qualities/behaviors you admire in a discussion leader. Write down three that you think are very important.

1)

2)

3)

Some discussion situations will be freer than others. For example, after a presentation, the purpose of the discussion may be to answer questions not fully explained in the presentation. In this situation, the discussion is usually free and relatively unguided.

In another situation, the "presentation" may be the discussion itself. Before leading this type of discussion it is a good idea to decide what you want to discuss and in what order. You should write an agenda of everything you want to cover in the discussion. Present the agenda at the beginning of the discussion and keep it in view throughout the discussion so that everyone can follow the discussion.

Exercise 2

A list of possible agenda items is below. Look it over and then write your own agenda. What would you add to your agenda that isn't on this list? What wouldn't you include? In what order do you want the discussion topics?

- Beliefs about and experiences with breast cancer
- Beliefs about and experiences with mammogram
- Mammogram versus breast self exam
- Fears
- Obstacles to getting a mammogram--cost, transportation

Take 5 to 10 minutes to write your own agenda. Then, in groups of 3 to 5, discuss what you have written for about 15 minutes. Finally, come together as a whole group and talk about the "highlights" and questions that came up within your groups.

SOS ADVISOR ROLE

How to Lead a Discussion with Small Groups Using the Brochure

BCSP-Save Our Sisters:
Group Discussion For Peace of Mind

1. Getting Started

Thank people for coming, make sure everyone knows each other. Try to create a warm, friendly atmosphere.

Show the BCSP-SOS brochure and explain that it is about breast cancer in the Black community. Tell them that you belong to a group called Save Our Sisters, which is trying to raise awareness about the importance of mammograms in detecting breast cancer early when survival rates are higher.

2. Distribute the Brochure

After giving them a moment to look at the brochure, try to begin a discussion about it. Talking about the brochure will help women think about it, and will also raise questions for discussion. Sometimes people just start talking right away. Other times, you need to get the conversation started with some questions. Here are some example questions that you might ask to get the conversation going. You don't have to use all of the questions in order to get a good discussion going among the women. There is no right or wrong answer to these questions.

What do you think of the brochure?
What do you or don't you like?
What do you think the main message is?
Did you learn anything new?
What part stood out as especially important to you?

Other good questions: _____

_____

_____

_____

SOS ADVISOR ROLE

Discussion with Small Groups Using the Brochure (continued)

3. Go over the worksheet, "Getting Your Mammogram"

The worksheet has been put together to help women learn and remember some important facts about breast cancer. It is for them to keep, and the things they write will be only for their use. Go over each section of the worksheet, one at a time. Make sure that the women understand the important points in each section.

a. Why Get a Mammogram

This section of the worksheet includes some of the most convincing statistics on why a woman should get a mammogram. There are two main points to emphasize:

1. Breast Cancer is a disease that many women get. We are all at risk.

2. Breast Cancer is a disease that has higher survival rates if it is detected early with a mammogram.

Ask women to fill in the blank with their age.

It is important to make sure women understand the second point. It does not help women to frighten them without showing them a way to deal with the problem.

b. When to Get a Mammogram

The worksheet shows the National Cancer Institute (NCI) Guidelines for when and how often a woman should get a mammogram. Ask the women to put an "X" in the box next to the age group that applies to them.

Go over the NCI recommendations for each age group. Make sure to explain what a "clinical exam" and a "breast self-exam" are.

This is a good time to ask the women to think about whether they have done what the guidelines recommend for their age group.

SOS ADVISOR ROLE

Discussion with Small Groups Using the Brochure (continued)

c. What Keeps Me From Getting a Mammogram

Go over the common reasons why women don't get mammograms. Ask women whether any of these reasons have been reasons why they haven't had a mammogram in the past. Encourage them to talk about their own reasons, and when appropriate make some suggestions about how to overcome the barriers.

It is very important not to be judgmental. Have respect for the women's fears and concerns. Try to understand their point of view before making any suggestions.

d. How to Get a Mammogram

As shown on the worksheet, there are two ways for a woman to get a mammogram. She can either ask her doctor to refer her for one or she can ask you who can help her get one. Some women don't feel comfortable saying they don't have a doctor, so explain both of the possibilities.

Many doctors don't yet follow the NCI guidelines for mammography screening. If a woman calls her doctor and tells him/her about the guidelines or brings the worksheet to her next appointment, most doctors will refer the woman for a mammogram. If for some reason s/he does not, women should contact you.

Other important mammography facts:

- In the Martin area, screening mammograms cost between $55 and$60.
- The accredited radiology centers in the area are Martin General Hospital and Eastern Radiology.
- North Carolina state law now requires that private insurers pay for mammograms according to the NCI guidelines, but usually the woman has to meet a $10 or $200 deductible first. For this reason, it is usually better to schedule a mammogram late in the year, when the deductible has already been met by other things.
- Medicare also covers mammograms.

SOS ADVISOR ROLE

Discussion with Small Groups Using the Brochure (continued)

4. Ending the Meeting

The last thing you want to do before the meeting ends is ask the women over 50 who have not had a mammogram this year if they will leave their names and numbers so you can contact them to schedule a mammogram.

SOS ADVISOR ROLE

Discussion with Small Groups Using the Brochure: A Leader's Guide

1. Create a warm, friendly atmosphere.

2. Distribute the brochure, generate discussion.

3. Go over the worksheet, "Getting Your Mammogram."

   A. Why Get a Mammogram
   B. When to Get a Mammogram
   C. What Keeps Me from Getting a Mammogram
   D. How to Get a Mammogram

4. Ask women over fifty who have not had a mammogram this year to leave their names and phone numbers so that you can contact them to schedule a mammogram.

Getting Your Mammogram

Why

BECAUSE breast cancer is the leading cause of death for most adult women (those between 35-75).

My age is: _____

AGE is the biggest risk factor for breast cancer. As you get older, your chances of having breast cancer increase. At 50, a woman has a 200 times higher risk for breast cancer than a 20 year old.

BUT, when detected early with a mammogram, 95% of women are treated successfully.

Why some women don't

Women have many reasons why they haven't gone to get their mammograms yet. Here are some of the most common ones:

* no referral
* fear of the results
* fear of treatment
* not having a physician for follow - up

Things that have kept me from going:

_____

_____

When

40 or younger:

Clinical breast exam every 3 years

Breast self-exam every month

40-50 years:

Women under 50 should talk to a health care provider about their need for a mammogram

Clinical breast exam every year

Breast self-exam every month

50 and older:

Mammogram every year

Clinical breast exam every year

Breast self-exam every month

How

If you have a regular doctor:

Ask him/her for a referral for a mammogram according to the NCI guidelines.

If you don't have a regular doctor:

Contact an SOS Advisor today!

My advisor's name:

_____

My advisor's phone number:

_____

BCSP-SOS Advisor Training Program

Washington County, North Carolina

Schedule

Role of the SOS Advisor

- Working as a Team

SOS ADVISOR ROLE

Working as a Team: What is Consensus?

What is Consensus?

Consensus is a way to make group decisions without voting.

Agreement is reached by:

- Gathering information
- Listening to different viewpoints
- Discussion
- Persuasion
- Combining different ideas or developing totally new ones.

The goal of consensus is to reach a decision that everybody agrees with.

Consensus does not always mean total agreement. A group can proceed with an action without having reached total agreement. Those who don't agree can decide to join in the action for the sake of solidarity or they may "stand aside" and let the rest of the group go ahead. In either case, the group hears their objections before going ahead.

Consensus decision-making sometimes requires a great deal of patience. It is necessary to listen carefully to opposing viewpoints to reach the best decision. It often takes a lot of time and commitment. In spite of this, however, there are some real advantages to consensus decision-making.

Advantages to Consensus Decision-Making

- ◆ It produces "thought-through" decisions, by including everyone's best thinking.
- ◆ It avoids situations where someone has to win and someone else has to lose. This keeps the unity of the group intact.
- ◆ It raises the chances for coming up with new and better ideas because it pushes past "the first thing that came to mind."
- ◆ It increases commitment to going through with the decision because everybody has participated in making the decision.
- ◆ It lowers the chances of the minority feeling that a decision was forced on them.

SOS ADVISOR ROLE

Working as a Team: Tips for Consensus Decision Making

Encourage the discussion of viewpoints, especially when they may be in conflict.

- Draw out those who do not speak.
- Face the differences in opinion openly. (A real consensus comes only after facing the differences.)
- Try using the "small group to large group" method.

Listen carefully for agreement or hesitation within the group.

- When a decision cannot be made, repeat the points of agreement and the points of hesitation.

Look for agreement when a decision seems to be emerging.

- Say what the decision seems to be, in the form of a question, and be specific.
- Ask for help if you are not clear on how to word the decision.
- Insist on a response from the group.
- Don't take silence to mean agreement.

When there is no agreement, ask those who disagree to offer alternative proposals for discussion.

- People may need time to reflect on their feelings. Propose a short break or period of silence.
- If you decide to put off making a decision, set a specific time for returning to the discussion.
- Sometimes opposing groups can work together to reach a compromise proposal. When one or two people are blocking consensus, ask if they are willing to stand aside, to let the group proceed with the action.

SOS ADVISOR ROLE

Working as a Team: How to Have Good Meetings

Using the T.E.A.M.S. Method

Meetings are an important part of SOS Advisor activities. In meetings, you may pass on breast cancer information, identify women's health concerns in their community, and build plans to carry-out solutions to those problems. You will meet with many different people in the community. You could meet with church groups, women's groups, seniors groups, health workers, and with other SOS Advisors.

Using a method like T.E.A.M.S. to plan a meeting, helps make sure that the group accomplishes its objective and that everyone's input is included. It also helps avoid the problem of boring meetings by including some things that are fun and surprising. Listed below are some tips for planning with T.E.A.M.S.

Time

- Is the agenda clear to everyone?
- Is there enough time to accomplish the objectives of the meeting?
- Is there work time, break time, individual thinking time, and group discussion time?

Events

- Is there a clear beginning and ending to the meeting?
- Are there awards, songs, food, games, celebrations, or other events to refresh people?
- Is there a balance of lively activities and reflection events?

Accomplishment

- What is the purpose of the meeting?
- Is the focus of the meeting clear to everyone?
- Is the expected product well-defined?

Method

- Are the methods designed to maximize participation?
- Are the methods well-suited to the desired outcome or product?
- Will the methods encourage a decision and clear next steps?

Space

- Does the seating arrangement promote participation?
- Is the space clean, uncluttered, comfortable, and exciting to be in?
- Are all the supplies, visual aids, and materials prepared?

BCSP-SOS Advisor Training Program

Washington County, North Carolina

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Schedule

Health Knowledge

- In-Reach

What is it and why is it important?

A Look at the Providers

Making an Appointment

Navigating the System

The Breast and Cervical Cancer Control Program

HEALTH KNOWLEDGE

In-Reach: A Look at the Providers

Exercise 1a

"I'm going to read things to you that the Washington County Health Department staff said during their interviews and I want you to tell me if it's a benefit or a drawback. Okay? Does everyone understand?" [Take time to decide if it's a benefit or a drawback). The Washington County Health Department staff said:

Benefits:

- Health Department services emphasize prevention and screening.
- All women get education about breast cancer as part of their exam.
- All women who come to the Adult Health clinic get a breast exam.
- Clients are taught breast self-exam.
- The Health Department sends a letter or calls to reschedule missed appointments.
- The Health Department follows up on clients who have been referred elsewhere.
- If a breast abnormality is found during an exam, the Health Department will call the woman's doctor and schedule an appointment; if a woman doesn't have a doctor, the Health Department will schedule an appointment with Dr. Agee, a local surgeon.
- The Health Department participates in community outreach efforts related to breast cancer.
- Women can usually get an appointment within two weeks.
- Funds are available from the state (BCCCP program) to help women pay for mammograms if they meet the income requirements.
- Women who are eligible for the special state funds can get a mammogram referral directly from the Health Department, without having to go see a doctor.

Drawbacks:

- The Health Department now charges a small fee for services, based on a sliding fee scale.
- An annual exam can take as long as two hours.
- Women who are eligible for the special state funds that pay for mammograms can be referred by the Health Department only to Martin General Hospital or to the mobile mammography unit brought into Washington County.

HEALTH KNOWLEDGE

In-Reach: A Look at the Providers (continued)

Keeping up to date about the current situation in Washington County is one of your responsibilities. Remember that the Washington County Health Department is making an effort to improve its services to better meet the community's needs. Its good faith efforts are one reason that BCSP's In-reach efforts are focused on the Health Department.

Another important point to keep in mind is that you have an expertise all your own--you can do something that none of the health care providers can do: Outreach. You have been selected because you are respected by, listened to, and connected with the people in your communities. As a consequence of who you are and the training you have received, you have great power to reach the women of Washington County and give them "peace of mind."

HEALTH KNOWLEDGE

Making an Appointment

To make an appointment at the Washington County Health Department, there are some basic steps to keep in mind (see below).

Exercise 2

Each table has an envelope labeled "Washington County Health Department." In the envelope, there are five steps for making an appointment written on separate pieces of paper. (Each piece of paper has one of the steps written on it.) Your job is to figure out the correct order for the pieces. Take the pieces out of the envelope and put them in order on your table.

The Washington County Health Department in Plymouth:

❶ Call 793-4949 or 793-3023, Monday through Friday from 8:00 to 5:00.

❷ The phone operator will answer "Health Department, may I help you?"

❸ Tell the phone operator you want to speak to a clerk to make an appointment for an Adult Health check-up.

❹ Tell the clerk that you want to make an appointment to get a clinical breast exam and a referral for a mammogram.

❺ The clerk will make the appointment.

If you are eligible for the special state funds that help women pay for mammograms, you must get a pap smear as well as a clinical breast exam. If you have had a recent pap smear at a doctor's office, you can give the Health Department the results so that you don't have to have another one.

If you are having a breast problem, ask for Susan Lilly, the Adult Health nurse. If she is not available, the phone operator will take your name and phone number and Ms. Lilly will call you back as soon as possible. When you talk to Ms. Lilly, she will ask you about the problem you are experiencing and either schedule an appointment for you at the Health Department or refer you to a doctor if she thinks that is necessary.

The Washington County Health Department does not do mammograms itself. However, it can refer women to radiology centers and to doctors, and make women's mammogram appointments.

HEALTH KNOWLEDGE

Navigating the System: Private Doctors

Although there are only four private doctors in Washington County, some women go to one of those doctors or go outside the county to see a doctor. If a woman has her own doctor and wants to get a clinical breast exam and a mammogram referral, she should go to her doctor.

If a woman doesn't have a doctor and wants to get a clinical breast exam and a mammogram referral, she should go to the Washington County Health Department (see "Making an Appointment").

If a woman doesn't have the money to pay for a mammogram but wants to get a mammogram referral, she should go to the Washington County Health Department, and ask about the special state funds that help eligible women pay for mammograms (see "In-Reach: A Look at the Providers"). However, the special funds can only be used if women get a mammogram at Martin General Hospital or use the mobile mammography unit brought in by the MTW Health District (see "The Radiology Centers").

HEALTH KNOWLEDGE

Navigating the System: The Radiology Centers

In-reach also includes coordination with local radiology centers about their procedures. The centers described below are either accredited or in the process of getting accredited. Being familiar with these centers and how they operate is important information to have when you go out into your community. The prices quoted are subject to change and are for screening mammograms; the prices will be different for diagnostic mammograms.

A woman may request from any radiology center that an additional copy of her mammogram results be sent to the Washington County Health Department if she goes there, or would like to go there for care.

Mobile Mammography Van

- Brought into Washington County by the Martin-Tyrrell-Washington Health District.
- Call the Washington County Health Department at 793-3023 for an appointment.
- The mobile unit comes in four times a year, for a full day in Washington County.
- Up to 60 women per day can be scheduled for a mammogram at the mobile unit.
- If a woman does not have a doctor, the mammogram results will be read and followed up at the Health Department.
- Women can ask for Susan Lilly, the Adult Health nurse at the Washington County Health Department, or Marlene James at the Martin-Tyrrell-Washington Health District, if they have questions.
- Cost: $57, or $55 if paid for by the special state mammogram funds.

HEALTH KNOWLEDGE

Navigating the System: The Radiology Centers (continued)

Washington County Hospital

- Located on East US 64 in Plymouth.
- Call 793-4135 for an appointment.
- Washington County Hospital will accept appointments made by patients themselves (self-referral). But, if a woman makes an appointment for herself, she must have a doctor who can follow up on the results.
- Women can ask for Yvonne Cooper, the radiology technician, if they have questions.
- Women whose mammograms are paid for using the special state funds cannot get a mammogram at Washington County Hospital at this time.
- Cost: $30 hospital charge, $57 radiology charge = $87 total.

Martin General Hospital

- Located at 310 S. McCaskey Road in Williamston.
- Call 792-2186, extension 536 for an appointment.
- Mammography is generally by appointment, but there is also a "walk-in" clinic every Wednesday.
- Martin General Hospital will accept appointments made by patients themselves (self-referral). But, if a woman makes an appointment for herself, she must name a doctor who will follow up on the results. If the woman does not have a doctor, Dr. Agee, a staff surgeon, will read and follow up on mammography results.
- If the woman does not have a doctor, she can get a mammogram referral from the Health Department, and the mammogram results will be read and followed up at the Health Department.
- No cash is required for a mammogram, the hospital will bill insurance.
- If the woman has no insurance, the hospital will do the mammogram and work with her on a payment schedule.
- Martin General Hospital has four technicians who are trained to do mammography.
- Women can ask for Cheryl Mitchell if they have questions.
- Cost: $60.

HEALTH KNOWLEDGE

Navigating the System: The Radiology Centers (continued)

Exercise 3

With a detailed map of Washington County, mark the locations of the Washington County Health Department, Washington County Hospital, and any private doctors you know about. Take a few minutes when you're done and discuss which ones are easy or hard to get to. Does anyone have any hints or suggestions for situations when transportation is a problem?

HEALTH KNOWLEDGE

The Breast and Cervical Cancer Control Program (BCCCP)

The goal of the North Carolina Comprehensive Breast and Cervical Cancer Control Program (BCCCP) is to reduce breast and cervical cancer. BCCCP has provided the Washington County Health Department with funding. The money comes from the Centers for Disease Control and Prevention (CDC) in Atlanta, with matching funds from the local agencies.

Who can BCCCP pay for? The target population for the program is older minority women who are less than 200% above poverty and uninsured or underinsured. Women aged 40 and older are eligible for breast cancer screening.

What is the function of BCCCP? The program's activities include paying for screening and follow-up services like mammography, clinical breast exams, pelvic exams, pap smears, diagnostic mammograms, and fine needle aspiration.

The North Carolina Comprehensive Breast and Cervical Cancer Control Program (BCCCP) 's Sliding Fee Scale is shown below. If you make less than or equal to the amounts shown below, you are eligible for BCCCP funds.

Size of Household	Income per month	Income per year
1	$1227.	$14,720.
2	1640.	19,680.
3	2054.	24,640.
4	2467.	29,600.
5	2880.	34,560.
6	3294.	39,520.
7	3707.	44,480.
8	4120.	49,440.
For each additional person in households with more than 8 people add this amount per person:	2,480.	4,960.

HEALTH KNOWLEDGE

The Breast and Cervical Cancer Control Program (BCCCP)

In Washington County, the Martin-Tyrrell-Washington Health District and the Washington County Health Department have a contract with the North Carolina BCCCP. This means that women who meet the income eligibility requirements can go to the Health Department and get a clinical breast exam, a pap smear, and a mammogram referral (no one can receive BCCCP money without getting these things). If a woman has no doctor of her own, the Medical Director at the Health Department will read the mammogram results and follow up with the woman. To receive BCCCP assistance, a woman must go to the Health Department.

The BCCCP program can also pay for mammograms for women who have insurance (either Medicare/Medicaid or private insurance) but who have not met their deductible.

BCSP-SOS Advisor Training Program

Washington County, North Carolina

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Schedule

Health Knowledge

- Medicare and Medicaid and How the Health Care System Works

HEALTH KNOWLEDGE

Medicare: Some of the Basics

MEDICARE

Medicare is our country's health insurance program for people over 65, and for certain people under 65 with disabilities, and for people of any age with permanent kidney failure.

WHO IS ELIGIBLE?

Most people 65 or older are eligible for **Medicare Hospital Insurance (Part A)** based on their own - or their spouse's - employment.

If you are already getting Social Security retirement or disability benefits or railroad retirement checks, **the Social Security Office** will contact you a few months before you become eligible for Medicare and give you the information you need to sign up.

If you are not already getting checks, you should contact the **local Social Security Office** about 3 months before your 65th birthday to sign up for Medicare.

HEALTH KNOWLEDGE

Medicare: Some of the Basics

MEDICARE HAS TWO PARTS: PART A AND PART B:

Medicare Part A or Hospital Insurance

Eligible persons who are enrolled in Medicare are automatically covered by the Hospital Insurance or Part A. Medicare Hospital Insurance can help pay for inpatient care in a hospital or skilled nursing facility, home health care, and hospice care.

Medicare **does not pay for ALL health care costs.** In each instance there are **benefit periods, deductibles, and coinsurance amounts.**

A **deductible** is the amount a person must pay **before** Medicare begins paying.

Coinsurance is the portion of the bill that the person is required to pay even after the deductible is met.

You can get specific information about Medicare costs, deductibles, and coinsurance rates by calling the local **Social Security Office.**

HEALTH KNOWLEDGE

Medicare: Some of the Basics

Medicare Part B or Medical Insurance

Anyone who is 65 or older - or who is under 65 but eligible for hospital insurance - can enroll for Medicare Medical Insurance **by paying a monthly premium.**

You are automatically enrolled in Part B when you become entitled to Part A. However, because you must pay a monthly premium for Part B coverage, you have the option of paying for it or turning it down.

The current monthly premium is $46.10 per month. This can change from year to year.

Initially you have 7 months to sign up for Medicare Part B. This 7 month period begins 3 months before your 65th birthday, includes the month you turn 65, and ends 3 months after that birthday. **If you don't enroll during this initial enrollment period, each year you are given another chance to sign up during a general enrollment period from January 1 through March 31. Your coverage begins the following July!**

Medicare Part B helps pay for doctor's services and many medical services and supplies that are not covered by the hospital insurance part of Medicare, such as ambulance services, outpatient hospital care, and X-rays.

HEALTH KNOWLEDGE

Medicare: Some of the Basics

Each year, before Medicare Medical Insurance begins paying for covered services, you must meet the **annual medical insurance deductible.** The "deductible" is the amount a person must pay before Medicare begins paying. After you **meet the deductible,** Medicare will generally pay **80% of the approved charges for covered services** for the remainder of the year.

In 1994, the yearly deductible was $100.

HEALTH KNOWLEDGE

Medicare: Some of the Basics

WHAT MEDICARE DOES NOT COVER

Medicare provides basic health care coverage, but it does not pay all of your medical expenses. Here are example of what Medicare **does not pay for:**

- "custodial care"
- most nursing home care
- dental care and dentures
- routine checkups and the tests related to check ups (except that Pap smears and mammograms are covered)
- most immunizations
- most prescription drugs
- routine foot care
- tests for, and the cost of, eyeglasses or hearing aids
- personal comfort items, such as a phone or TV in your hospital room.

HEALTH KNOWLEDGE

Medicare: Some of the Basics

MEDICARE MEDICAL INSURANCE (PART B) PAYMENTS

The Assignment Payment Method

Under the assignment method, your doctor or supplier agrees to **accept the amount approved by the Medicare carrier as total payment for the covered service.** The doctor agrees "to take the assignment".

The doctor sends the claim to Medicare. Medicare pays your doctor the **80% of the approved Medicare amount,** after subtracting any amount of the annual $100 deductible you have not met. **The doctor can only charge you for the part of the deductible you have not met and for the coinsurance, which is the remaining 20% of the approved amount.**

Doctors and suppliers sign agreements to become **Medicare participants.** Medicare -participating doctors have agreed in advance to accept assignment on **all Medicare claims.**

If your doctor does **not accept Medicare assignment,** you must pay your doctor directly. You are responsible for the part of the bill that is more than the Medicare approved amount since your doctor did not agree to accept the Medicare-approved amount as payment in full.

HEALTH KNOWLEDGE

Medicare: Some of the Basics

COVERED SERVICES FOR BREAST CANCER SCREENING, DIAGNOSIS AND TREATMENT

Mammography

Medicare Part B helps pay for X-ray **screenings** for the detection of breast cancer, if they are provided by a Medicare-approved supplier. Women over 65 can use the benefit **every 24 months.** Medicare also pays for **diagnostic mammograms as needed when symptoms are present.**

Medical and Surgical Services

Medicare also helps pay for doctor's services related to the care and treatment of breast cancer, including **mastectomy. Breast reconstruction** is not a covered service unless it is a medical necessity.

Biopsies, Other Diagnostic Tests

These are covered services when ordered by your doctor to evaluate your medical problem.

Laboratory Tests and X-Rays

Laboratories must be certified under the Clinical Laboratory Improvement Amendments to perform laboratory testing. Medicare pays the full approved fee for covered diagnostic tests.

Radiation Therapy

Chemotherapy

HEALTH KNOWLEDGE

Medicaid : Some of the Basics

MEDICAID

Medicaid is a program that pays the medical bills for eligible low income people who can't afford the cost of health care. It is run by the state through the Division of Medical Assistance.

WHO IS ELIGIBLE?

Clients who receive checks for Aid to Families with Dependent Children (**AFDC**), and clients who receive Special Assistance to the Blind are eligible for Medicaid.

Others who may be eligible include:

- Persons receiving State/County Special Assistance for Adults
- Persons receiving Supplemental Security Income (SSI)
- Other **aged (65 and older), blind or disabled persons who have limited income and other assets**
- Families with children under 21 when their incomes and assets are low
- Children under 21 in foster homes
- Pregnant women with low income

How Are Payments Made?

No money is paid to the client. The eligible client gets a Medicaid identification card through the mail to show the doctor or other medical care provider. The provider sends his bills to the state and the state pays for the service.

HEALTH KNOWLEDGE

Medicaid : Some of the Basics

Where and How Do I Apply?

Apply at the Department of Social Services in the county in which you live. You must sign an application and give information about your family and income.

The county agency will determine if you are eligible.

Items you should take to the agency when applying include:

- birth certificate or other proof of age
- wage stubs
- social security card
- forms which show amount of income from social security, SSI, retirement etc.
- life and medical insurance policies
- savings books and bank statements
- information on ownership of property and motor vehicles

The intake worker at the Department of Social Services can tell you how much income and how much reserve assets you can have and still be eligible.

HEALTH KNOWLEDGE

Medicaid : Some of the Basics

What Health Services Are Covered?

1. **Inpatient Hospital Services.** Pre-Admission Review is required before you can be hospitalized for non-emergency care.
2. **Inpatient laboratory and X-ray.**
3. Hospice Care
4. Home Health Care
5. Six (6) prescription drugs per month
6. **Annual physical exams for adults.**
7. A total of 24 visits to health care providers for covered services per year.
8. **Screening mammograms every 2 years; diagnostic mammograms as often as needed based on symptoms.**

Be sure to ask your provider if he accepts Medicaid before you receive services. **If he does not accept Medicaid, you will be responsible for the bill.**

You will receive a blue Medicaid ID card for each month you are eligible. Show the provider the Medicaid card each time you go for services. **If you do not show the provider the card, he can charge you for the visit.**

A small fee, called a copayment may be charged for some services (i.e. $3.00 for each outpatient hospital visit).

HEALTH KNOWLEDGE

Medicaid and Medicare: Some of the Basics

QUESTION	MEDICAID	MEDICARE
What is Medicaid/ Medicare?	• Medicaid is a program that pays medical bills for eligible low income people who can't afford the cost of health care. • Medicaid costs are paid by federal, state and county taxes.	• Medicare is health insurance for people over 65 and some disabled people. • Medicare has two parts: (1) Part A (hospital insurance) covers inpatient care, skilled nursing facility care, home health care, and hospice care. This part is for all people over 65. (2) Part B (medical insurance) covers doctors' services, outpatient hospital service, and some other services not covered by Part A. This part is optional and has a monthly fee. **Part B covers the cost of a mammogram.**
Who is eligible?	• Receiving Medicaid depends on a person's income, not their age. You can be any age and receive Medicaid. • To be eligible, a person must meet income and assets limits, and/or be: --aged (65 or older), or --blind, or --disabled, or --a pregnant woman, or --a member of a family with dependent children.	• All persons over the age of 65. • Some disabled people.
Who is it run by?	• Medicaid is run by the state through the Division of Medical Assistance in the Department of Human Resources.	• Medicare is run by the federal government through the Social Security Administration.
Where do you apply?	• Contact the Social Services office in Plymouth (793-4041).	• Questions about Medicare can be directed to the national Social Security Administration (toll free number: 1-800-772-1213).

How is Medicaid different from Medicare?	Some people are covered by both Medicare and Medicaid. Medicaid can pay the Medicare deductible and co-insurance, and the Part B premium for persons who are eligible for both Medicaid and Medicare. However, most people are eligible for either one or the other, not both.

HEALTH KNOWLEDGE

Medicaid : Some of the Basics

MEDICARE-AID

Medicare-Aid is a free benefit under the Medicaid program that supplements Medicare coverage for low income individuals. It pays for:

Medicare Parts A and B Premiums

Medicare Deductibles

Medicare Coinsurance Charges

Who Qualifies For Medicare-Aid?

Individuals or couples who:

- Have Medicare Parts A and B coverage, or
- Are entitled based on age or disability for Medicare but have not signed up
- Have income below 100% of the federal poverty level
- Have assets (other than home and motor vehicle) valued below $4000 for individual or $6000 per couple

HEALTH KNOWLEDGE

Medicaid : Some of the Basics

Where Does Someone Sign Up for Medicare-Aid?

Application for this benefit is made at the county Department of Social Services in the county of residence.

To apply for this benefit you must fill out an application and provide information about income and other eligibility requirements.

Take the following items when you go to apply:

- Social Security and Medicare cards
- Records of income
- Copies of bank and savings statements
- Life insurance policies
- Deeds or other records of property ownership
- Copies of medical bills

HEALTH KNOWLEDGE

Medicaid : Some of the Basics

What Services Are Covered By Medicare-Aid?

Medicare-Aid will pay the portion of charges not paid by Medicare and owed by you. **This coverage works like a "supplement" to Medicare. It pays premiums, coinsurance, and deductibles.**

- **Premiums will no longer be deducted** from your Social Security checks.
- The annual **$676 deductible for Part A** hospitalization will be paid by Medicare-Aid.
- The annual **$100 deductible for Medicare Part B** will be paid.
- Medicare-Aid will pay for the **20% coinsurance** for most medical expenses that Medicare does not pay.

HEALTH KNOWLEDGE

Medicaid : Some of the Basics

Special Help to Pay Medicare Part B Premiums

MQB-B

There is also a provision for Medicaid to pay **only the Medicare Part B premiums** for eligible persons. The basic eligibility requirements are the same as for Medicare-Aid. The income limits for this program are between 101% and 110% of the federal poverty level.

HEALTH KNOWLEDGE

How the Health Care System Works

Services	Payment
For Women with No Breast Problems	
Yearly mammogram	Medicare pays every other year for women 65 years and older Payment in installments can be negotiated at some mammogram centers
Yearly breast exam by health professional	Payment in installments can be negotiated at some clinics
For Women Who Suspect a Breast Problem	
Exam by doctor	Payment by insurance company or Medicaid Medicare pays for women 65 years and older Payment in installments can be negotiated at some clinic
Mammogram	Payment by insurance company or Medicaid Medicare pays for women 65 years and older Payment in installments can be negotiated at some mammogram centers

HEALTH KNOWLEDGE

How the Health Care System Works (continued)

Services	Payment
For Women With Breast Problems	
Biopsy by doctor	Payment by insurance company or Medicaid Medicare pays for women 65 years and older Payment in installments can be negotiated at some clinics and hospitals
For Women with Breast Cancer	
Other tests and cancer treatment	Payment by insurance company or Medicaid Medicare pays for women 65 years and older Payment in installments can be negotiated at some clinics and hospitals
For Women Treated for Breast Cancer	
Regular check-ups Breast Reconstruction (if wanted)	Payment by insurance company or Medicaid Medicare pays for women 65 years and older Payment in installments can be negotiated at some clinics
Social support groups	No charge

WASHINGTON COUNTY
MEDICAL PROVIDERS

Down East Surgical Associates	4 Medical Plaza Plymouth, NC 27962 (919) 793-9730
Dr. Robert N. Agee **Dr. Victor R. Stelmack**	
Office Hours	9:00 a.m. - 5:00 p.m. Monday - Friday By appointment only
Medicaid	Accepts Medicaid
Medicare	**Accepts Medicare and Medicare Assignment**
New Patients	Accepting new patients

****

Dr. Myung-Kil Jeon	Hwy 64 East Plymouth, NC 27962 (919) 793-5073
Office Hours	7:30 a.m. - 4:30 p.m. Monday - Thursday 7:30 - 11:30 a.m. Friday Appointment is necessary
Medicaid	Accepts Medicaid
Medicare	**Does not accept Medicare**
New Patients	Accepting new patients

****

Roanoke Medical Center **Dr. Chang Y. Oak** **Dr. Robert Venable** **Dr. Michael G. Fisher**	Hwy 64 East Plymouth, NC 27962 (919) 793-4500
Office Hours	8:00 a.m. - 5:00 p.m. Monday - Friday. By appointment only
Medicaid	Accepts Medicaid
Medicare	**Accepts Medicare and Medicare assignment.**
New Patients	Accepting new patients

****

BCSP-SOS Advisor Training Program

Washington County, North Carolina

SAVE OUR

S.O.S.

SISTERS

FOR

PEACE OF MIND

Schedule

Role of the SOS Advisor

- Finding Out What Works

SOS ADVISOR ROLE

Finding Out What Works

Four times a year we ask all BCSP-SOS advisors to tell us about the counseling and other activities about mammography or breast cancer they have done with women.

Every 3 months a one page questionnaire (front and back) is sent with a newsletter to all advisors. The newsletter will keep you up to date on BCSP-SOS activities.

This short questionnaire asks you, as an advisor, to check off the counseling and presentations about mammography or breast cancer you have done since we last asked you.

The questionnaire's purpose is to describe, for other people and for your group as a whole, how SOS advisors make our project work. What you describe will also help us improve the program as we move it into other counties.

We are interested in knowing about:

- Any presentations you made to groups of people about mammograms or breast cancer **in the last 3 months**, where you did this and what you talked about.
- How many different people you talked with about mammograms or breast cancer **in the past week**, what you talked about, who they were and how you helped them.
- What materials you used and where you found the women you talked to.

This questionnaire is **not** a check up on advisors. All advisors are volunteers from their communities who devote their time to this project at their convenience; they can do as much or as little as their schedules permit. We know there will be times when you can spend very little, or no, time on SOS activities. That doesn't matter. Your help, whenever you can give it, is very valuable to us. We want your participation in BCSP-SOS to be meaningful to you. Thanks for your willingness to fill out these questionnaires.

Your name _____

NC-BCSP Health Advisor Activity Report

1. Did you make a **presentation** to any group of people about mammograms or breast cancer in the **past 3 months**? Check ✓ "yes" or "no."

   no ___ → **STOP! Go to Question 6 at bottom of this page.**

   yes ___ → How many different times did you talk to groups about breast cancer **in the past three months**? → _____
   ↓ Write number of talks here

2. Where did you talk to the groups? Check ✓ all the places where you talked.

   _____church _____work _____ senior center

   _____some other place _____
   Write the name of the place

3. Were most of the women in the groups: Check ✓ one.

   _____over age 50 _____under age 50_____ half were over, half were under 50 years old

4. What did you talk about? Check ✓ all the topics you talked about.

   ___ Who needs a mammogram
   ___ Where to get a mammogram
   ___ How to pay for a mammogram
   ___ How often to get a mammogram
   ___ Problems getting a mammogram
   ___ Signs of breast cancer
   ___ Treatment for breast cancer
   ___ SOS/NC-BCSP health advisors (who they are, what they do)
   ___ Some other subject? _____
   What was it?

5. What materials did you use? Check ✓ all that you used.

   ___ SOS video___ SOS video worksheets___ SOS tee shirt___ *Do the right thing* button___ brochures

6. Did you talk with anyone **individually** about mammograms or breast cancer **during this past week?** (Don't count people you talked to at a presentation.) Check ✓ "yes" or "no."

   no ___ → **STOP! Please return this form to Evelyn in the enclosed envelope this week.**

   yes ___ → How many different women did you talk with about breast cancer or mammograms **during this past week?** _____
   ↓ (turn page) Write the number of individual women you talked to.

7. Were most of the women you spoke to **in this past week**: _____ under age 50 or _____ over age 50

8. How many of them were: Write numbers of each group you talked to. If "none" in a group, put "0".

_____ family _____ friends _____ church members _____ co-workers _____ strangers

9. When you talked to the women, which of the following did you do? Check ✓ all that you talked about.

___ Encouraged someone to get a mammogram

___ Talked about fears of getting a mammogram

___ Talked with someone who has breast cancer

___ Talked about health problems that were not breast cancer

___ Talked about getting involved in SOS/NC-BCSP

___ Talked about something else_____
What else did you talk about?

10. Which of the following did you **explain**? Check ✓ all that you explained in the past week.

___ Which women need mammograms

___ Where to get a mammogram

___ How to pay for a mammogram

___ How often to get a mammogram

___ Problems getting mammograms

___ Signs of breast cancer

___ Treatment for breast cancer

___ SOS/NC-BCSP health advisors (who they are, what they do)

11. Which of the following did you **suggest**? Check ✓ all that you suggested in the past week.

___ Someone to contact for further help or information

___ Something to read about mammograms or breast cancer

___ Something else? _____
What was it?

___ Where to get treatment

___ Where to get a mammogram

12. Did you help the people you talked to in other ways? What did you do? Check ✓ all that you did as an SOS/BCSP Advisor **during this past week**.

___ Arranged for transportation for a woman to get a mammogram

___ Set up an appointment for a mammogram

___ Other ways you helped?_____
Please explain what you did

___ Thought of a way to pay for a mammogram

___ Found some other kind of services

Please return this form to Evelyn Neptune in the enclosed envelope as soon as you fill it out.

Thank you very much for filling out these pages!

BCSP-SOS Advisor Training Program

Washington County, North Carolina

SAVE OUR

S.O.S.

SISTERS

FOR

PEACE OF MIND

Schedule

Role of the SOS Advisor

- Finding Out What Works

SOS ADVISOR ROLE

Finding Out What Works

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- How many different people you talked with about mammograms or breast cancer **in the past week**, what you talked about, who they were and how you helped them.
- What materials you used and where you found the women you talked to.

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Your name _____

NC-BCSP Health Advisor Activity Report

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   yes ___ → How many different times did you talk to groups about breast cancer **in the past three months**? → _____
   Write number of talks here

2. Where did you talk to the groups? Check ✓ all the places where you talked.

   _____church _____work _____ senior center

   _____some other place _____
   Write the name of the place

3. Were most of the women in the groups: Check ✓ one.

   _____over age 50 _____under age 50_____ half were over, half were under 50 years old

4. What did you talk about? Check ✓ all the topics you talked about.

   ___ Who needs a mammogram
   ___ Where to get a mammogram
   ___ How to pay for a mammogram
   ___ How often to get a mammogram
   ___ Problems getting a mammogram
   ___ Signs of breast cancer
   ___ Treatment for breast cancer
   ___ SOS/NC-BCSP health advisors (who they are, what they do)

   ___ Some other subject? _____
   What was it?

5. What materials did you use? Check ✓ all that you used.

   ___ SOS video___ SOS video worksheets___ SOS tee shirt___ *Do the right thing* button___ brochures

6. Did you talk with anyone **individually** about mammograms or breast cancer **during this past week?** (Don't count people you talked to at a presentation.) Check ✓ "yes" or "no."

   no ___ → **STOP! Please return this form to Evelyn in the enclosed envelope this week.**

   yes ___ → How many different women did you talk with about breast cancer or mammograms **during this past week?** _____
   Write the number of individual women you talked to.

↓ (turn page)

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What else did you talk about?

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___ Where to get a mammogram

___ How to pay for a mammogram

___ How often to get a mammogram

___ Problems getting mammograms

___ Signs of breast cancer

___ Treatment for breast cancer

___ SOS/NC-BCSP health advisors (who they are, what they do)

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___ Someone to contact for further help or information

___ Something to read about mammograms or breast cancer

___ Something else? _____
What was it?

___ Where to get treatment

___ Where to get a mammogram

12. Did you help the people you talked to in other ways? What did you do? Check ✓ all that you did as an SOS/BCSP Advisor **during this past week**.

___ Arranged for transportation for a woman to get a mammogram

___ Set up an appointment for a mammogram

___ Other ways you helped?_____
Please explain what you did

___ Thought of a way to pay for a mammogram

___ Found some other kind of services

Please return this form to Evelyn Neptune in the enclosed envelope as soon as you fill it out.

Thank you very much for filling out these pages!

CHAPTER 6

COMMUNITY ACTIVITIES

The Health Educator and the Lay Health Advisors will often collaborate on projects to increase mammography screening in the county in which you work. This will be done through a series of community activities designed to empower the community.

The following chapter has been adapted from the **Save Our Sisters** manual on planning a mobile mammography van campaign. This campaign is an example of the type of community activities you will want to plan.

There will be many tasks to perform so that you will have a successful and rewarding mobile mammography screening day. This manual describes the details of each task.

I. FORM A PLANNING GROUP

A) Group Size

-the ideal group would be approximately 6 to 8 people who have worked together before or who belong to one or more of the organizations that wish to sponsor a mobile mammography van screening day.

B) Group Characteristics

-It is important that this planning group be able to:

- Organize and keep track of all the planning details;
- Recruit and assist enough helping hands to carry out the tasks which need to be done;
- Divide up the responsibilities and have weekly check-in meetings; and
- Enjoy the excitement of working hard together for the next four months.

C) At the First Meeting.....

-Decide on a time and place for the mobile mammography van site (you'll want some alternatives just in case the van is booked).
-Some of the tasks you will want to start thinking about include: raising funds, advertising, and signing women up for the campaign.
-Decide on a time and place for the next meeting to start the planning process.
-Decide who in the group will lead the next meeting.

II. CONTACT AND SELECT A RADIOLOGY SERVICE

-You will want to discuss the following information with the radiology service:

- Find out if they are willing to go to the area in which you plan to have the screening day(s). Some radiology services only travel within a one hundred mile radius from where they are located.

- Payment for mammograms. Some services will file insurance claims and only require that the women have their insurance number and card available.

  Be sure to find out if there are any insurance policies that the radiology service will not accept. This is very important because some women may work for a business that has an unacceptable insurance plan.

  If your organization will be assisting women who cannot pay for mammograms, the radiology service should be notified of this before the screening day.

- Space requirements for the mobile van. Most mobile vans have to be parked in a large, vacant parking lot. They have their own electrical supply.

- If the mammography screenings will be done for more than one day, arrangements should be made for providing room and board for the technicians. Usually, the organization sponsoring the screening days is responsible for paying for room and board, but discuss with each radiology service to see how they handle this.

III. RAISING FUNDS FOR A MOBILE MAMMOGRAPHY SCREENING DAY

Some of the women who will want to have a mammogram on the screening day(s) may not have any health insurance and may not be able to pay the full cost of a mammogram. Groups/organizations usually find it difficult to turn these women away because they are the women who most need to have a mammogram. Here are some guidelines for making the payment process during the screening days less complicated.

A) Medicare Clients. It is most beneficial for Medicare clients if screening days are scheduled toward the end of the calendar year. By this time, most clients with Medicare should have reached their deductibles. Medicare only pays for a mammogram every two years.

Some radiology facilities will waive the small fee they charge when clients have reached their deductibles. It is important to find out from the radiology facility whether, prior to the screening days, they can check to find out if clients have met their Medicare deductibles. This helps to reduce any confusion surrounding billing after the screening days.

B) Bank Account. You will want to obtain a bank account, you should solicit assistance from a bank to obtain an account free of charges to place funds obtained from various fundraising activities.

C) The **Save Our Sisters** program targeted black women in their churches and asked churches for contributions to fund mammograms for women who could not afford to pay. February 14, 1993 was designated Sister Sunday in black churches in Wilmington.

D) The **Save Our Sisters** program placed advertisements in high school reunion announcements, explaining what they do and asking for financial support of **Save Our Sisters.**

IV. ADVERTISING

A) Timing. Advertising should be started at least six weeks before the event.

B) Target. Your group/organization has to determine where the women you would like to reach are most accessible, for example through the churches. You may want to consider advertising in church bulletins.

Another possibility is advertising in black newspapers or on radio stations. Someone can create a public service announcement to be aired on black radio stations, especially during times when older black women tend to listen, for example, during early morning church shows.

Previous efforts at reaching black women for screening involved advertising on billboards, television stations, and all local newspapers. Those efforts proved to be ineffective for reaching black women. In fact, the majority of women that showed up for mammograms were white.

C) Lay Health Advisors. The Lay Health Advisors can also actively recruit clients through their social networks.

V. SIGNING UP WOMEN FOR MAMMOGRAPHY SCREENING

The following are some suggestions on how to recruit women from churches for the campaign.

A) Set up a schedule of appointments with at least 15 minutes for each appointment. There should be a half an hour lunch break scheduled for the mobile van technologists.

B) Contact the pastor of the church and explain that your group/organization is trying to improve mammography screening among older, black women. It is helpful if the person contacting the pastor is a member of his congregation, but it is not a requirement. Male pastors are sometimes uncomfortable discussing breast cancer with the women in the congregation, so they may refer you to their wives, the church secretary or women's group in the church.

C) Ask the pastor if an announcement about the mobile unit campaign can be placed in the church bulletin. The announcement should state the date(s) and time(s) of the mammography screening campaign, as well as how women can sign up to receive a mammogram.

D) When signing up women for the mammography screening campaign it is important to remember that older black women are very secretive about their health and do not want to discuss it with strangers or acquaintances. This poses a problem when trying to sign up women for mammography screening in a place other than a doctor's office, thus it will require sensitivity on the part of those volunteering on the campaign.

More women are likely to sign up if asked to fill out a small slip of paper during the church service and place it in the collection plate. The slip of paper should be an attachment to the church bulletin that they can easily remove. It should have spaces for their names, addresses, and phone numbers.

E) The women who filled out slips are then contacted by phone. They should be asked their age, their mammography history, insurance information, and whether or not the woman has a regular physician.

- Age. According to the National Cancer Institute (NCI) guidelines, a woman should have a mammogram every year after her fiftieth birthday.

- Mammography History. If a woman has received a mammogram less than year prior to the upcoming event, she should be educated about the frequency of having mammograms, and informed when they should return for a mammogram. Insurance plans will not pay for more than one mammogram a year.

- Insurance Information. If the woman is elligible for a mammogram, obtain insurance information from her, i.e. type of insurance - Medicare, Medicaid, or other insurance policy.

- Whether or Not the Woman Has a Regular Physician. Some people may not have a doctor, so your organization may have to solicit the assistance of physicians in the community; their role would be to receive the results of mammograms from the radiology facility and follow-up with the woman. The radiology facilities usually have a radiologist who reads the results of the mammogram.

F) After all of this information has been obtained, schedule an appointment for the woman. Be sure to remind her to show up on time. Also instruct the women not to use any powder or perfume in their underarm or breast area on the day that they will be getting a mammogram. Powder or perfume make a mammogram picture unclear. In addition, remind the women to wear comfortable clothing, peferrable a blouse and skirt or slacks.

G) If possible, all women who scheduled an appointment should be contacted at least three days before the screening event to remind them that they have an appointment.

H) Some mobile mammography facilities may want a schedule of the appointments prior to the screening days so that they can generate

some of the paperwork in advance. This helps to expedite the registration process on the day of the event.

VI. THE MAMMOGRAPHY SCREENING DAY

Members of your organization should try to plan every minute of the screening day(s) to prevent any suprises or complications.

A) There should be one to two people responsible for reminding women of their appointments at least 3 days prior to the screening day.

B) There should be at least 2 members of your organization at the site of the mobile van to greet women and direct them to the check-in area. Your organization should have a complete schedule of appointments and a list of the method of payment for each individual available on the screening day. The list should be used to check off every woman that arrives and control the flow of traffic into and out of the van. (Most vans can only hold 3 people comfortably, including the technician and those in the waiting area)

C) When the time of an appointment has arrived, one to two members of your organization should escort the woman into the van. This may seem to be a waste of time, but for women who have never had a mammogram, it allows them to discuss any fears or embarrassment they may be experiencing surrounding getting a mammogram. This is also a good time for the woman to be told what will happen when she enters the van.

D) After the woman has had her mammogram, it is important that a member of your organization ask her informally, what her experience was when having a mammogram.

E) There should also be a formal questionnaire that women are asked to complete after they have had the mammogram. It should ask how the woman heard about the screening day(s) and what were their experiences with this screening day.

There should be one or two people solely responsible for making sure that every woman is asked if she would like to complete a questionnaire.

Some of the women being screened may not e able to read or write, so when approaching them about completing the questionnaire, simply ask them if there are any questions you do not understand and I can read them to you or ask if you can fill out the questionnaire for them.

F) Media coverage allows the community as a whole to become more aware of the organization sponsoring the screening day, i.e. publicizes the organization and what its role is in the community. If your organization has a public relations person, that person usually knows how to contact local radio and TV stations and newspapers as well as make national media contacts. However, not all groups have a public relations person, so those organizations will have to designate someone who can make the necessary contacts.

It is important to schedule reporters, photographers, and cameramen from each station or newspaper at different times, with at least 30 minutes between each appointment. This helps reduce the confusion of too many people getting in the way of mammography screenings. Your organization should have a written statement describing the organization and why you are sponsoring the screening day. The statement should be given to each station or newspaper a few days prior to the event. Most media groups request such a statement prior to covering an event.

Some members of your organization (1-2) should be solely responsible for working with the media. They will be responsible for conducting interviews with reporters and determining where and with whom photographs should be taken. The privacy of all women receiving mammograms is the first priority; they should decide themselves whether they want to be photographed or quoted. Media groups should provide a release for women to sign if they are photographed or quoted.

VII. AFTER THE SCREENING DAY(S)

Your organization has completed a successful mammography screening day! The work is not all done. There are still loose ends that need to be tied up.

A) Thank you notes should be sent to all organizations, groups, or individuals who made financial or other contributions to the screening event.

B) The mobile mammography facility will begin to notify women and their doctors of the results of the mammograms. Your organization may also be able to obtain the names of women with suspect readings. However, confidentiality must be maintained. The radiology facility is responsible for contacting women with suspect readings for a follow-up or diagnostic mammogram. If the woman chooses to call your organization to notify you of her results, then you can intervene and assist the woman as needed.

C) Last, but not least, keep a list of all the women who received mammograms during this screening campaign and one year from now, send them reminders that they need to have another mammogram. Some radiology services will send your group/organization a list of women who received mammograms to help you with this.

Community Outreach Specialist and Lay Health Advisor Training

NEW
TRAINING MANUAL

Breast & Cervical Health
Session 1

Agenda

- **Arrival/Gathering** (20 min)
- **Welcome, Introduction & Overview** (10 min)
- **Ice Breaker: Paired Interviews** (30 min)
- **Establishing Group Norms** (5 min)
- **History of Piedmont Health Services and Sickle Cell Agency (PHSSCA)** (20 min)
- **What is an LHA?** (40 min)
- **Breast and Cervical Health: Statistics** (15 min)
- **Risk Factors** (40 min)
- **Closing/Evaluation** (15 min)

Learning Objectives

- **Find out what training is about**
- **Learn about the history of PHSSCA**
- **Discuss what makes a good LHA**
- **Understand why breast and cervical cancer are important health concerns**
- **Talk about risk factors for breast and cervical cancers**

Total Time

3 hours and 15 minutes, plus 10-minute break

Handouts

- **Breast health statistics (#1A)**
- **Cervical cancer statistics (#1B)**
- **Risk factors (#1C)**
- **Breast and Cervical Cancer: The Basics (Session 1 summary -- #1D)**
- **Talking with a friend (Homework assignment -- #1E)**

Flipchart Templates

- **Overview of training**
- **Session 1 learning objectives**
- **Session 1 agenda**
- **Ground rules**
- **Parking lot**
- **Pluses & Wishes**

Trainer's Notes	

Arrival/Gathering

Trainers:

Time: 20 minutes

Background: The workshop incorporates 20 minutes for arrival, sign-in, and gathering. At the end of the 20 minutes, participants should be gathered at the table and ready to begin the workshop.

Training Objectives:

At the end of this activity trainers will have:
1. Completed logistical aspects of the workshop.

Materials:

- Name tags
- Pens, Markers
- Stickers
- Sign-in sheet
- Refreshments
- Extra copies of pre-workshop survey and consent form

Steps:

1. Make sure the room is set up before participants begin arriving.
2. Have person(s) greet participants as they arrive.
3. Have table with registration materials clearly displayed. Have all participants sign in and put on name tags when they arrive.
4. Have any participant who has not completed a pre-workshop survey or signed a consent form do so at this time.
5. Encourage participants to eat and mingle.
6. Inform participants 5 minutes before the start of the session activities so they can begin gathering at the table.

	(Note to facilitators: As part of the recruitment process, each potential participant should be asked if she needs any special accommodations to ensure her attendance and full participation. For example, close parking or handouts in large print. As people arrive, make sure any such special needs have been met and make additional arrangements if necessary.)

Trainer's Notes	

Welcome, Introduction, & Overview

Trainers:

Time: 10 minutes

Background: The purpose of this section is to help participants feel welcome at the training and introduce them to the scope and logistical aspects of the training.

Training Objectives:

At the end of this activity trainers will have:

1. Welcomed and introduced participants to the training.
2. Provided a brief overview of the entire training and what each session will cover.
3. Reviewed the goals for the entire training.
4. Reviewed the objectives and agenda for session 1.
5. Explained staff roles.
6. Begun to establish a comfortable learning environment.

Materials:

- Flipchart sheets
- Overview of all four sessions (flipchart page)
- Session 1 learning objectives (flipchart page)
- Session 1 agenda (flipchart page)

Steps:

1. After everyone is seated, welcome and thank them for coming. Acknowledge the value of their time and effort in attending the training.

    ♦ We are going to start now. Welcome to the first session of the NC-BCSP training. Thank you very much for being here. We know you all are very busy and your time is important, so I really appreciate your attendance.

2. Ask the group for permission to open the session with a prayer. If the group agrees, ask one of the participants to lead the prayer.

    ♦ In the past we have often opened and closed each of our training sessions with a prayer. Would you all like to open and close your training sessions with a prayer?

- Would someone from the group like to lead us in the opening prayer today?

3. Start with a brief introduction of names. Ask everyone (including trainers, notetakers, observers, etc) to briefly say her first and last name. Go around the circle until everyone has said her name.

   - We are going to spend a lot of time getting to know each other over the course of this training, but I'd like to start out by just having everyone in the room introduce themselves by saying their first and last name. I will go first. My name is _____.

4. Talk to the group briefly about breast and cervical health and why this training was developed.

   - As you all know, we are here to learn about breast and cervical cancer, and to develop the skills to be lay health advisors for early cancer detection.

   - This training is part of a larger project called the North Carolina Breast Cancer Screening Program, which is called BCSP for short. You may also know this project as Save Our Sisters. The project takes place in five counties: Beaufort, Bertie, Martin, Tyrrell and Washington. The project also has an office in Chapel Hill at UNC. Some of you here are very familiar with this project and have been volunteers with the project for several years. Others may be less familiar with the project. We are going to talk more about the history of the project later.

   - This training was developed to build on the efforts of BCSP's current lay health advisors, or LHAs. For eight years, about 160 volunteers, including many of you here today, have been working to prevent breast cancer by educating and advising the women in their communities about the importance of mammography. Now, we are hoping to build on their success and refresh some of the existing LHAs and train some new LHAs to not only be breast cancer LHAs, but also cervical cancer LHAs.

   - If you aren't familiar with some of these terms, such as lay health advisor or cervical cancer, don't worry. We will be learning about all of that in great detail over the course of the training.

5. Explain trainer roles.

   - Once again, my name is _____ and this is _____. We will be the lead trainers throughout most of the training sessions. Our job is to provide information, ask questions, answer questions, and lead the discussions and activities. We will be present at all of the sessions, though at times other staff members or volunteers with the project will be leading activities.

   - Even though we are the trainers, we do not have all of the answers. I don't think any one person does. However, by working together, we can usually answer a lot of each other's questions. So, please ask questions, especially if you don't understand something. If we don't know the answer, we'll try and find the answer before the next session.

6. Explain notetaker.

   - _____will be at every session and her job is to take notes. She is taking notes about the workshop, however, and NOT about you individually. The comments she writes will help us know which parts of the training went well and which parts we might want to change for future trainings.

7. Explain participants' roles.

   - This workshop was designed to build upon the knowledge and experience you already have. So, your role in the training is to participate. There will be many opportunities for you to share your experiences and knowledge to help the group learn and I hope you will feel comfortable doing so.

8. Tape flipchart pages with the overview and goals of the entire training to the wall. Briefly explain what each of the training sessions will cover and the goals of each session.

   - The training consists of four sessions. Each session will present a lot of new information and skills. The sessions are designed to build on one another, so it is important for you to attend all four sessions. Each session is about three hours long.

   - Session 1: Breast and cervical health
     Session 2: Early detection
     Session 3: Lay health advising

	Session 4: Getting around the health care system & survivor panel ♦ We also have a graduation ceremony planned for _____. It will be a time to celebrate your accomplishment in completing the training and becoming an official lay health advisor for NC-BCSP. The ceremony will include LHAs who completed the training in other groups or at different times. Your family members and friends are all invited to the ceremony. 9. Review the learning objectives and agenda for today's session. Post flipchart sheets on wall. ♦ Today we'll be covering…(refer to learning objectives) ♦ To cover all of that, we have a very full agenda…(refer to agenda) ♦ We will have a scheduled break here (refer to agenda), but if you need to use the restroom or take a break to walk around at any other time, please do so. But please hurry back because we have a lot of exciting activities planned. ♦ The restroom is located… 10. Lead into next activity. ♦ Now that I've gone over some of the basics of the training, let's get to know each other better.

Trainer's Notes	

Ice Breaker: Paired Interviews

Trainers:

Time: 30 minutes

Background: This ice breaker is an important activity for the first session of the training because it provides an opportunity for participants to get to know each other better, and for the trainers to learn more about the participants and the participants to learn more about the trainers. This activity helps establish trust among group members and allows everyone's voice in the room to be heard and valued. This activity also helps lay the groundwork for a comfortable learning environment.

Training Objectives:

At the end of this activity trainers will have:

1. Set the foundation for trust among participants.
2. Enabled participants and trainers to introduce themselves to each other regarding areas that are relevant and important to the training.
3. Worked toward establishing a comfortable learning environment where everyone's voices and experiences are valued.

Materials:

- Flipchart
- Markers
- Cards cut into halves
- Chime

Steps:

1. Explain that the next activity is an exercise to get to know each other better.

    - ♦ I know some of you here know each other very well already and others may not know each other at all. But, there is always something new we can learn about each other. We're going to try to get to know each other better by interviewing each other in pairs.

2. Ask the group to think about things they would like to know about other people in the room.

	♦ What are four things we would like to know about the people here? 3. Write list down on the flipchart. Examples might be where they're from, how long they've been involved with BCSP, community involvement, hobbies, etc. 4. If it hasn't been mentioned, be sure to add to the list what participants hope to learn from the training. ♦ An important thing for the trainers to know is, "What is one thing you hope to learn in this training?" Please add that to the list of questions you ask your partner. 5. Before breaking the group into pairs, explain the interview process. ♦ Before we break into pairs, let me explain how the interviews will work. You will interview your partner to try to get the answers to the list of questions we just created, and then your partner will interview you. Pay close attention because after the interviews, you will be introducing your partner. ♦ I will keep track of time and let you know when to switch interviewing. Each person should get about four minutes to interview her partner and then 1 minute to check what she heard. I will sound a chime, to let you know when it's time to switch interviewers. After both partners have interviewed each other, we will come back together as a large group and each person will introduce her partner. 6. Pass out cards (only enough for each participant to have a one half of a matching card). Break into pairs by asking each person to take one half of a card and to pair up with the person that has the other half of their card. ♦ Please take one half of a card. To find your interview partner, find the person with the other half of your card. You may want to spread out within the room. Once you have found your partner, begin the interview. 7. Keep track of time and announce when 4 minutes have passed and the interviewer has 1 minute to check what she heard. After 1 minute pass, announce "switch." Let the second interviewers know when 4 minutes have passed. After 1 more minute, sound the chime.

	8. Sound chime. Bring attention back to the whole group. ♦ Please come back to your seats, so we can hear about everyone in our group. 9. Have each person briefly introduce her partner to the whole group. *(Note to trainer: A one-minute hourglass, sitting on the front table, could be a visual reminder to keep participants to their time limit. Otherwise, they are likely to talk and talk, lengthening this section.)* ♦ I would like for each of you to introduce your partner and tell us one thing you found most interesting about her and what she hopes to learn from the training. I will make a list of what everyone hopes to learn. You have about one minute to introduce your partner. I will let you know when your time is up. 10. Write down participants' expectations, or "what they hope to learn from the training," on the flipchart. 11. Thank the participants for sharing, then review the list of expectations. State which expectations are beyond the scope of this training and confirm those that will be covered. ♦ Thank you all for sharing. It is exciting to hear about everyone's different experiences. ♦ As you know, we have a lot to do in a short amount of time. It looks like most of the things you hope to learn are in line with what we have planned. The only things we will not be able to cover due to limited time and scope of the training are (_____). However, if you want more information on these topics, we can help you find some resources. 12. Lead into next activity. ♦ Getting to know everyone in the group better is important for creating a comfortable and safe learning environment. Something else that contributes to this kind of environment is a set of ground rules.

Trainer's Notes	

Establishing Group Norms

Trainers:

Time: 5 minutes

Background: Creating a comfortable learning environment is essential so that participants feel safe taking risks in learning, contributing their experiences, and openly asking questions. Establishing group norms, or ground rules, is one way to help create a safe training environment.

In the interest of time, a list of ground rules will be presented to the group; however, participants should have the opportunity to add ground rules to the list at this first session and as the training progresses. The list should be clearly written and visibly posted at every training session. Trainers should refer to the ground rules at the beginning of every session and ask the group if there are any changes they would like to make to the list.

Training Objectives:

At the end of this activity trainers will have:
1. Created a safe and comfortable learning environment.
2. Introduced the concept of the "parking lot."
3. Clarified time management issues.

Materials:

- Flipchart with ground rules written on it
- Markers
- Parking lot (blank flipchart except title)
- Chime
- Toys (placed on table before participants arrived)

Steps:

1. Explain to the group what ground rules are and why it is important to have them.

    - ♦ Ground rules, or group guidelines, help us work well together. It is important for us to have ground rules that we agree to use throughout this workshop, so that this is a comfortable learning environment for everyone and we can accomplish tasks efficiently.

2. Present flipchart with list of ground rules. Ask participants to add ground rules to the list.

   - I created a list of a few ground rules that other groups have found helpful. These include:
     -Start and end on time
     -Listen
     -Ask questions if something is unclear
     -Don't interrupt
     -No comment or question is stupid
     -It's okay to disagree, but do so respectfully
     -Respect everyone's ideas and opinions

   - What are some other ground rules that you would like to add to this list to help us all work well together over the next 4 training sessions? Are there any ground rules already on this list that you would like to change?

3. Write additional ground rules suggested by the group on the flipchart. Once the list is complete, ask participants if they have any questions or need clarification on any of the ground rules. Ask the person that suggested the ground rule to make the clarification.

4. Ask participants if they agree with the ground rules. Discuss any ground rules that participants do not feel good about.

   - It is important that we all feel good about our ground rules. Please raise your hand if you agree to follow these ground rules over the course of the training.
     (Note to facilitator: If someone does not raise her hand, ask her if there is a specific ground rule that she is not comfortable with. Ask her how she thinks it should be changed. Ask participants if they agree with the change.)

5. Tape list of ground rules to the wall so that everyone can see it. Tell participants that the ground rules will be used throughout the training; however, trainers or participants can add or change the ground rules any time.

   - Great! It is helpful to have these ground rules from the beginning. They will be posted at every session so that we are all aware of them. We can change the ground rules as we think of new ones or as we realize that old ones do not fit our needs.

6. Clarify the process for upholding the ground rules.

- Remember, the ground rules are here for everyone to follow. If any of us forgets to use a ground rule, it is up to us to remind that person of the ground rule. Trainers may make a comment if they think someone is not using a ground rule; however, trainers may also need to be reminded of them. We will also point out the ground rules to any guests that attend our sessions.

7. Introduce the concept of the parking lot.

   - The ground rules will be very helpful for accomplishing tasks efficiently. However, we have a lot to cover in this training and every session is filled with a variety of activities. This can be good and bad. It is good because we will do a lot of different things. It is bad because there may not be time to discuss everything we want to discuss.

   - To help solve the problem of topics that are brought up that we are not able to cover immediately, we have a "parking lot." You don't park your valuable car in a parking lot and leave it there forever; you <u>always</u> come back for it. And that is what we'll do with questions and topics we put in our parking lot here. It's a place to keep track of questions we cannot answer or solve at the moment they come up and other issues that we plan to address later in the training program. It is also a place to write down topics that are related to but not exactly what we started out discussing. The parking lot is very helpful in keeping us on task and in making sure we cover all the important topics.

   - We will bring the parking lot to each session. We will keep track of the items that are put in the parking lot and try to address each point to the best of our ability given the time and scope of the training.

8. Clarify time management issues.

   - We will be doing a lot during the training. My role is to keep the workshop moving and on time. If we start running short on time, I may ask you to summarize your point so that we can move on. However, you can talk with me or each other after the sessions.

   - Also, if you have to come late or leave early, please let me know. It's important for the group to know if people won't be here.

	9. Introduce items on the table. ♦ You may have noticed that there are a variety of items on the tables. It may seem a little strange to have these toys and markers on the tables since these are items that children usually play with. These toys are here for *you*, though. Some people think that learning must be serious and no fun. But, that is not the case in this training. ♦ I realize that these training sessions may seem rather long, and that it can be hard to "sit still" the whole time. So, the toys are there for you to play with if you want to use your hands during the training. I won't take the sight of you playing with the toys as a sign of boredom. Rather, I realize that we all learn in different ways and need different levels of physical activity while we learn. So, please use the toys as much as you want. I only ask that you don't distract others. ♦ Each of you should also have a folder, paper, and pen in front of you. The paper is for taking notes and the folder is for keeping any notes or handouts from the training. ♦ The last thing I want to introduce is the chime. As you heard, the chime will be used to bring your attention back to the large group when we are doing small group activities. 10. Lead into the next activity. ♦ Now that we have written our ground rules, established our parking lot, and explained the room set-up, let's move on to an activity that reminds us why we are here in the first place.

Trainer's Notes	

History of Piedmont Health Services and Sickle Cell Agency (PHSSCA)

Trainers:

Time: 20 minutes

Background: This section provides an overview of the PHSSCA including the agency's history and how it became involved in the project. Some of the participants may already be familiar with the project, while others may be less familiar. It is important that all participants are aware of the groundwork that has been laid by the project and the reason we're doing this training. Participants will be given the opportunity to ask the project director questions.

Training Objectives:

At the end of this activity trainers will have:

1. Provided participants with an overview of PHSSCA and the project.
2. Established the historical context for the training.
3. Allowed participants to ask project trainers questions about the PHSSCA project.

Materials:

- "Breaking the Silence" video
- TV
- VCR

Steps:

1. Explain to participants that it is important to know about the history of the project for which they are being trained to be LHAs.

- As you all know, this training is part of the PHSSCA breast and cervical cancer training project. You also may know that BCSP has been active in eastern NC for nine years. For most of you, this may be your first encounter with the project.

- Regardless of how new or experienced we are with the project, it is important to understand what the project and its LHAs hope to accomplish within the next 6 months.

2. Provide brief background of the program and project.

- **Piedmont Health Services and Sickle Cell Agency originated in Greensboro, N. C. as Triad Sickle Cell Anemia Foundation, incorporated in 1972 and later was renamed Sickle Cell Disease Association of the Piedmont (SCDAP). The founding members included a mother of family members with the disease and her social club members who organized a support group to provide testing, education and genetic counseling and support services to individuals with sickle cell disease in the community. Sickle cell disease was thought to affect only African Americans at that time and very little knowledge was available about the treatment of the disease.**

- SCDAP participated in the establishment of Newborn Screening Guidelines for the state of North Carolina in 1994, when its Executive Director, Dr. Gladys Robinson, served as Chair of the North Carolina Council on Sickle Cell Syndrome, which secured state funding to support newborn screening. Initially developed as single race screening, the Council secured additional funding and the state instituted Universal Screening of all newborns. SCDAP has maintained a contract with the N.C. Sickle Cell Program since 1980. During the last 26 years, it has added Sickle Cell Comprehensive Case Management, the Sickle Cell Summer Enrichment Camp, Psychological Counseling, Career Counseling and Employment Assistance and Pediatric and Adult Home Teaching.

- **SCDAP has successfully provided this array of services to a caseload of over 500 patients and thousands of individuals who have sickle cell trait in the six county area. Its sickle cell caseload has become more diversified from 100% African Americans to 2% Hispanics and 1% Southeast Asians and 98% African Americans. Since 2000, the agency has been funded by HRSA to offer newborn screening follow-up services for infants/children with sickle cell disease.**

- **In 1993, SCDAP (PHSSCA) began providing HIV/AIDS Street Community and Outreach Prevention Education services in Guilford County.** Beginning with a Peer Education program for teens, the agency expanded its services to include HIV/AIDS in partnership with the Guilford County Health Department to provide street and community outreach, risk reduction education, and testing to high risk African Americans and Hispanics in High Point. Other HIV related services include:

- The Annual "Week of Prayer for the Healing of AIDS" initiated with over 100 churches in the African American Community.

- The agency was funded by CDC to provide HIV prevention services to African American substance abusers that are incarcerated or in drug treatment facilities.

- In May 2002, the agency joined local and state agencies through an intervention strategy in high risk neighborhoods to address the high rate of HIV and syphilis in Guilford County.

- In 2005, SAMHSA awarded a 4 year grant to provide HIV risk reduction services to individuals that were incarcerated or in substance abuse treatment centers, through 3 evidence-based interventions: Community Promise, Safety Counts, and Prevention Case Management. SISTA, another intervention, targeted HIV risk reduction for African American women.

- **In 2005, a partnership was developed with the United Way of Greater Greensboro to implement a new program, TAT (Thriving at Three) to address the needs of children 0-3 living in high risk family situations.** The program serves mostly African American young women (ages 16 -33), in collaboration with New North Carolinians (that serves Hispanic women, and offers one-to-one support to enable these families to become self sustaining and provide an enriching environment for the growth and development of their children.

- **In June 2007, the board of directors made a strategic decision to change the name of the agency to Piedmont Health Services and Sickle Cell Agency, and to adopt a new vision and mission.**

  - ***The vision is "****To become a leading community-based preventive health and outreach agency for all people"; and the* ***mission,*** *that addresses health disparities in minority communities is "PHSSCA provides outreach, education, screening and case management for people with high-risk health problems; focusing on sickle cell services, HIV/AIDS prevention and diabetes".*

- **As a 39 year old community health agency, PHSSCA provides services to six counties (Alamance, Caswell, Forsyth, Guilford, Randolph and Rockingham). The agency has evolved from**

primarily a sickle cell agency to a minority health agency to address the emerging health disparities in the African American community over the years. PHSSCA has three divisions: Sickle Cell Services, HIV Services, and Wellness Services.

- **In 2007 services were expanded to include a Screening and Wellness Program to meet the broader preventive health needs of the African American.**

- The initial clinic at the PHSSCA office in High Point (at Southside) began in 1998, when screening for HIV, syphilis, breast and male exams were offered to the indigent population in High Point in collaboration with the Guilford County Department of Public Health. In 2006 an additional clinic was added in the Greensboro office, to address the need for blood pressures, cholesterol and glucose. Some of the Wellness milestones include:

  - Colorectal cancer screening in collaboration with UNC Lineberger Comprehensive Cancer Center

  - In 2008 the agency received the SUCCEED Legacy Grant (via Morehouse School of Medicine in collaboration with UNC Chapel Hill) to provide breast cancer screening targeting women in the African American community. In partnership with the Guilford County Health Department's Breast and Cervical Cancer Control Program, the agency offers free breast and cervical screening at the Greensboro and High Point clinics for women age 50+ or those younger that are at high risk. To create awareness of cancer risks among African American females, the program will train lay health educators (AA women) to educate their civic or church groups about breast and cervical cancer.

  - Beginning July 1, 2009, clinic services will offer breast cancer screening for AA females and prostate cancer screening for African American males, through a 3 year grant from the North Carolina Health and Wellness Trust Fund. Lay health educators will be trained from women and men's groups in the community to broaden awareness.

3. Introduce and show video.

   ♦ Now we're going to watch a video called "Breaking the Silence." It shows the important work the BCSP LHAs do. Watch closely; you may recognize some of the faces you see.

	4. Ask participants if they have questions about the video. ♦ I hope that video gave you all some background on the project. Does anyone have questions about anything they saw on the video? 5. Lead into next activity. ♦ Now that we all are more familiar with BCSP, let's talk more specifically about what exactly an LHA is.

Trainer's Notes	

What is an LHA?

Trainers:

Time: 40 minutes

Background: The purpose of this section is to define the roles and responsibilities of LHAs and clarify the project's expectations of trained LHAs. This section does not begin LHA skill development, but rather focuses on what it means to be an LHA, from inherent qualities to the amount of time LHA activities consume.

Training Objectives:

At the end of this activity trainers will have:

1. Defined the roles and responsibilities of an LHA to her community.
2. Introduced the qualities and characteristics that an LHA should have.
3. Provided an opportunity for new LHAs to ask questions of experienced LHAs.
4. Clarified BCSP's expectations of trained LHAs.

Materials:

- Markers
- Flipchart paper
- Parts of the LHA bridge
- Sentence strips with characteristics of who LHAs are and what they do
- Labels for each end of the bridge: "Health care" and "Community"

Steps:

1. Write the following on a flipchart:
   Lay
   Health
   Advisor

2. Explain to participants what each word means.

   - ♦ You have been hearing us talk about LHAs or lay health advisors, but what does that really mean? Let's look at each word.

Lay: comes from the word "Laity" which means not ordained. We use this word to refer to church members who lead but are not ordained – such as lay ministers. It is also used to describe anyone who works in an area, such as health, who is not a professional. Our Lay Health Advisors are not professional health care providers.

Health: Health is defined by the World Health Organizations as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity." We think of health as a state of being – a quality of life.

Advisor: An advisor is a person who provides recommendations and information so individuals can make informed decisions. A person who is seen by others in the community as a "natural helper" – someone that others go to for guidance. An advisor serves as a bridge between women in the community and information they need to be healthy.

- So, our role as a lay health advisor in this program is to be an informed volunteer, not taking the place of a doctor or a nurse. Our responsibility is to help women stay healthy by advising them, within the scope of our training, – serving as a bridge - to help them understand the importance of breast & cervical health and the need to get regular screening tests (mammograms and Pap smears).

3. Lead into "Building the Bridge" activity.

   - Being a lay health advisor is a very special job. Being a good LHA means having certain qualities and characteristics. To better understand what makes a good LHA, we are going to do an activity called "building the bridge."

4. Explain activity.

   - On the sticky wall, as you can see, there are two ends of a bridge, but the bridge is not connected. One end of the bridge is your community and the other end is the health care system. As lay health advisors, you serve as the link-"the information highway" -- between the community and the health care system.

	♦ There are many qualities and characteristics an LHA needs in order to really be a bridge between her community and the health care system. Some are shown on these strips of paper. ♦ I would like for everyone to take one sentence strip. One at a time, place your strip on the sticky wall so that two ends of the bridge can be connected. Then, tell us how you think your sentence strip relates to being an LHA. Start your sentence with " A good LHA….." Once all the sentence strips are on the sticky wall, the bridge will be connected and we'll be able to see what characteristics and qualities it takes to be a good LHA and serve as a link between your community and the health care system. <u>Sentence strips:</u> -Is a good listener -Is trusted by others -Is respected by others -Is responsive to the needs of others -Is interested in women's health -Is caring and compassionate -Maintains close and supportive relationships with others -Is a good communicator -Is a good motivator -Understands how to access the health care system -Can balance the demands of lay health advising and other responsibilities 5. Pass out sentence strips. Have each participant explain what their strip says and place it on the sticky wall as a component of the bridge. Reinforce participants' comments about how each statement is an important part of being an LHA. 6. Thank participants for their participation in the activity. ♦ Thank you for helping to build this bridge. As you can see, it takes very special women who work very hard to create this bridge between the women in their communities and the health care system where they can receive preventive health care. 7. Invite existing LHAs to share their experiences as an LHA in their community. ♦ We've spent some time talking about characteristics and qualities of an LHA. Now I think it would be helpful to hear firsthand from experienced LHAs what it is like to be an LHA.

- I have some questions I would like to ask our LHAs and I want to invite you all to ask questions as well. Experience is often the best teacher, so I hope our LHAs will feel comfortable sharing some of their experiences.

8. Center discussion around the following questions while also allowing participants to ask their own questions.

   - What is the best part about being an LHA?
   - What is the hardest part about being an LHA?
   - How is being an LHA different from what you expected?
   - What else should new LHAs know?
   - What other questions do participants have?
   - **What do LHAs do?** (mention these activities if they do not come up in discussion – record on flip chart)
     -advise women one-on-one (in person and on the telephone)
     -wear beaded necklaces, t-shirts, and pins
     -talk to women in churches, at work
     -plan new activities with LHA group
     -give presentations at churches, nursing homes, women's groups
     -set up a booth at local events, like health fairs or county fairs
     -march in parades
     -pass out information at busy places, like the post office, church
     -attend LHA group meetings
     -talk to the COS about what they're doing

9. Tie in message about the power of working as a group.

   - As you can see from the list of activities we recorded, each LHA works very hard to protect the health of the women she knows and cares about. Some of these activities are individual things – like *advise women one-on-one*; some of these activities are group things – like *march in parades.* There is room for each woman, each LHA, to participate at a level that's comfortable and matches her personality. And when you think about all of us working together, it's really quite powerful. All of us working together as a group to promote breast and cervical health can reach a lot of women and really make a big difference.

10. Clarify BCSP's expectations of LHAs once they complete the training.

- All of you are here because you want to make a difference in the lives of the women in your community. However, some of you may have more time and some less. Also, some women may not feel comfortable doing all of the activities on the list we've made (like public speaking).

- We want to be clear that you should do as much or as little as you can, and do only those activities that you think you can take on.

- So, while we don't expect you to be involved in all of the activities on this long list we made, there are some that we ***do*** expect of you as an LHA for the Breast Cancer Screening Program.

- All LHAs are expected to:
  - **Advise** female friends, family members, and close associates about mammography
  - **Present herself as a resource**, so people can come to her and ask questions (ex. wear the beads from time to time; let others know she is an LHA)
  - **Attend regular LHA meetings**
  - **Keep her Community Outreach Specialist informed** about what she has been doing, so LHA efforts can be reported back to the project manager and funding sources

- We understand you are busy women, and you are volunteering your time for the benefit of others. Many LHAs have found that they can work breast and cervical health promotion into the things they are already doing, like talking to your women's club meeting, church circle, sorority meeting - for examples.

- Also, if you find that you can't make it to meetings or activities for a while, if you or a family member falls ill, let your COS know. You won't be dropped from the program. We say, "once an LHA, always an LHA." You may be able to pick up again when things improve.

11. Lead into break and next activity.

- You all are doing a great job. Before we move on, though, let's take a 10-minute break. Please be back here and seated by ____. When we return we'll talk in greater detail about breast and cervical cancers.

B R E A K

Trainer's Notes	

Breast and Cervical Health: Statistics

Trainers:

Time: 15 minutes

Background: This activity creatively demonstrates breast and cervical cancer statistics. While knowing specific numbers is not important, an awareness of the disproportionate impact of breast and cervical cancers on African American women is. This activity provides a visual demonstration of the discrepancies in rates between White women and African American women. Statistics of incidence and mortality are presented as a number out of 100,000 to make the demonstration more visual.

Because this activity requires handling a lot of materials, it is important to have two trainers implementing the activity. One of the trainers should explain the activity while demonstrating the cervical cancer statistics while the other trainer should do the visual demonstration for breast cancer statistics simultaneously. An alternative is to set up the paper dolls during the preceding break.

Training Objectives:

At the end of this activity trainers will have:

1. Defined breast and cervical cancer.
2. Visually demonstrated the discrepancies in breast and cervical cancer incidence and mortality rates between White women and African American women.
3. Emphasized the preventable nature of breast and cervical deaths.

Materials:

- Sticky wall
- Paper doll cutouts. Cutouts representing African American incidence and mortality rates and White incidence and mortality rates should be of different colors.
  - Row of 126 paper doll cutouts to represent breast cancer incidence for White women (per 100,000). On the back of 24 of these dolls are affixed blue dots, which represent breast cancer mortality for White women (per 100,000)
  - Row of 8 paper doll cutouts to represent cervical cancer incidence for White women (per 100,000). On the back of 3 of these dolls are affixed blue dots, which represent cervical cancer mortality for White women (per 100,000)
  - Row of 114 paper doll cutouts to represent breast cancer incidence for African American women (per 100,000). On the

back of 33 of these dolls are affixed blue dots, which represent breast cancer mortality rate for African American women (per 100,000)
- Row of 10 paper doll cutouts to represent cervical cancer incidence for African American women (per 100,000). On the back of 5 of these dolls are affixed blue dots, which represent cervical cancer mortality rate for African American women (per 100,000).

- Breast health statistics handout (#1A)
- Cervical cancer statistics handout (#1B)

Source for up-to-date data: Seer website http://seer.cancer.gov/

Steps:

1. Provide background for activity.

   - ♦ We're here today because we want to learn about breast and cervical cancer and use that information to help women in our community. Now, some of you may already know a lot about breast cancer and less about cervical cancer, and others may not know very much about either one.

   - ♦ Later today and in other sessions we are going to learn a lot about both cancers, including risk factors for getting cancer and how to find it early while it's still easy to treat. Right now, though, we want to talk about why it is important to address breast and cervical cancer in our community.

2. Explain cancer, cervical cancer, and breast cancer.

   - ♦ Cancer occurs when cells in the body change and grow out of control.

   - ♦ Breast cancer, then, is when cells in a woman's breast change and grow out of control. Cervical cancer is when cancer occurs in the cervix, which is a part of women's reproductive anatomy. We will be reviewing female anatomy in the next session.

3. Introduce activity.

   - ♦ As I mentioned, we are going to talk in a little bit about *why* cancer occurs. Right now, we're going to discuss why it's

important to address breast and cervical cancer in African American women.

- ♦ We could list off a bunch of numbers about how many women get cancer and die from cancer every year, but numbers are hard to remember. So, we've come up with another way to show you how African American women are affected by breast and cervical cancer.

4. Explain activity.

   - ♦ In thinking about how many women are affected by breast and cervical cancer, we should think about those women who get breast and cervical cancer, <u>those women whose lives could be saved by early treatment</u>.

5. Demonstrate breast and cervical cancer incidence in White women and African American women.

   - ♦ First let's look at breast cancer.

6. Demonstrate breast cancer incidence in White and Black women.

   - ♦ The first statistic we're going to talk about is the number of women out of 100,000 who **get** breast cancer in each year.

   - ♦ For African American women, this many people get breast cancer in a year. (Point to the 114 paper dolls up on the sticky wall. All dolls should display their plain sides – the blue dot sides come later on.)

   - ♦ In the same year, this many White women got breast cancer. (Show the line of 126 paper dolls on sticky wall that represent White women. Again, all dolls display their plain sides.)

   - ♦ How does the line of African American women compare to the line of White women? White women seem to **get** breast cancer more often than African American women.

7. Demonstrate difference in breast cancer mortality between White women and African American women.

   - ♦ Now let's look at how many White women and how many African American women are **dying** from breast cancer.

   - ♦ Out of 100,000 African American women, this many died from

breast cancer. (Now, turn over 33 doll cutouts of African American paper dolls to represent the mortality rate for black women – these 33 dolls have blue dots on their backsides to represent mortality.)

- For White women, this many people died from breast cancer. (Trainer flips over 24 White paper dolls to display the blue dots that represent mortality).

- When we talk about who **dies** from breast cancer, how does the line of African American women compare to the line of White women? More African American women are **dying** from breast cancer than White women. But, remember how many women got breast cancer. **Fewer African American women actually get breast cancer than White women, but more African American women are dying from the disease.**

8. Demonstrate cervical cancer incidence for African American and White women.

   - Now we'll look at the rates for cervical cancer and the differences between African American and White women.

   - For African American women, this many **get** cervical cancer in a year. (Trainer points to the row of 10 paper dolls up on the sticky wall.)

   - In the same year, this many White women got cervical cancer. (Now direct participants to the line of 8 paper dolls on sticky wall to represent White women.)

   - You can see that cervical cancer affects fewer women than breast cancer. You can also see that African American women are a little more likely to **get** cervical cancer than White women.

9. Demonstrate difference in cervical cancer mortality between White women and African American women.

   - Now let's look at how many African American and White women die from cervical cancer.

   - Out of every 100,000 African American women, this many **die** from cervical cancer each year. (Turn over 5 paper dolls to reveal the blue dots representing mortality.)

	♦ And this many White women die from cervical cancer. (Flip over 3 White paper dolls to show the blue dots.) ♦ What do you notice about these two lines? It doesn't look like many people die from cervical cancer, especially compared to breast cancer. But, it is important to notice that African American women are twice as likely to **die** from the disease than White women. ♦ We've all come together because women are dying from these diseases, and because African American women are more likely to die from breast and cervical cancer than White women. ♦ But, if breast and cervical cancers are found early and treated, lives are saved. 10. Emphasize the opportunity for reducing the risk of breast and cervical cancers through early detection. ♦ With both breast and cervical cancers, there are things we as women can do to lower our chances of getting and dying from them. The most important thing we can do is to get regular mammograms and Pap smears. These screening tests can notice breast and cervical cancer early while tumors or cell changes are small and easier to treat. We are going to spend a lot of time in the next session talking about cancer screening. 11. Lead into next activity. ♦ To understand what else we can do to protect ourselves from breast and cervical cancers, it is important to understand what puts women at risk for these diseases. The next activity will help us think about *why* some women get breast and cervical cancers and others don't.

Trainer's Notes	

Risk Factors

Trainers:

Time: 40 minutes

Background: This activity provides participants with an overview of the risk factors and signs/symptoms associated with both breast and cervical cancer. At a basic level, this section will cover what contributes to a woman getting breast and cervical cancers, and how a woman knows or suspects that she has breast or cervical cancer. As in most of the training activities in this curriculum, the information related to breast and cervical cancer is approached concurrently to encourage a holistic approach to women's cancer prevention. However, it is important that the trainer constantly reinforce those aspects of breast and cervical cancer that are distinct and those that are similar. Because this section covers a substantial amount of information, it is important to provide participants with a written summary of the information presented at the end of the activity. (See "Risk Factors" handout #1C.)

The trainer should be prepared to spend some time debunking myths about the causes of breast and cervical cancer that participants mention. For instance, women might believe that bruising the breast, whether from mammography or excessive manipulation by their partners, can lead to cancer.

Training Objectives:

At the end of this activity trainers will have:

1. Explained what risk factors are.
2. Identified what puts women at risk for breast and cervical cancer.
3. Identified early warning signs of breast and cervical cancers, but emphasized the asymptomatic nature of both cancers.

Materials:

- Blank ½ sheets of paper
- Colored ½ sheets with the following labels: breast cancer risk factors, cervical cancer risk factors
- Markers
- Colored gems (enough to break group into 2 or 4 groups)
- Risk Factors (Handout #1C)
- Breast and Cervical Cancer: The Basics (Handout #1D)
- brochure on HPV, if available

Steps:

1. Introduce activity.

    - Now let's talk about *who* gets breast and cervical cancers, *why* and *how* women know if they have either disease.

2. Introduce the concept of risk factors.

    - To understand why some women get breast or cervical cancer and others don't, we need to talk about risk factors. Risk factors are things that increase the chances of getting cancer; they can include: who we are (heredity) and what we do (behavior). Different cancers and diseases often have different risk factors.

    - As an example, think about smoking and lung cancer. Smoking is a risk factor; people who smoke are more likely to get lung cancer. But, not all people who smoke get lung cancer, and not everyone with lung cancer smokes. So, a risk factor is not <u>always</u> the cause, but it does increase your chances for getting the disease. A woman may develop breast or cervical cancer even if she has no risk factors. On the flip side, a woman with many risk factors will not necessarily develop cancer.

3. Explain activity.

    - To learn about the various risk factors for breast and cervical cancer, we are going to break into two/four groups: a breast cancer group and a cervical cancer group. Each group is then going to brainstorm all the risk factors they can think of for their topic. One person from each group should write down each risk factor on a ½ sheet of paper. It does not matter if the information is correct; just write down all the possible risk factors you can think of. We are then going to put all the ½ sheets up on the sticky wall and discuss them. So use large print so that everyone can read them from where they're sitting.

4. Use colored gems to break participants into two/four groups. Once they have formed their groups, give each group a stack of ½ sheets and a marker. Announce that they will have 5 minutes to discuss and write down risk factors.

5. At the end of 5 minutes, sound the chime to draw the attention back to the larger group.

6. Ask for two or three ½ sheets from each group and place them on the sticky wall under the appropriate category (breast cancer risk factors or cervical cancer risk factors). Group together any ½ sheets that have similar risk factors or that seem to "go together" under each category. (For example, if one group puts up "genetics" and another group puts up "family history" as risk factors for breast cancer, group them together.) *Do not discuss the risk factors yet. Simply get them on the wall in an organized manner.*

   Collect two or three more ½ sheets from each group and continue grouping them together on the sticky wall. Continue with this procedure until all ½ sheets are on the wall.

7. Discuss the risk factors now on the sticky wall, beginning with the breast cancer category. Read risk factors aloud and determine which are correct and which are incorrect. Remove those risk factors the group determines are incorrect. Group together any risk factors that are similar (e.g., both relate to heredity).

   <u>What are risk factors for breast cancer?</u>
   -Being a woman
   -Age (being older than 40)
   -Family history (mother, daughter, sister with breast cancer)
   -Never having children
   -Having first child after age 30
   -High fat diet
   -Being greatly overweight
   -Smoking
   -Not breastfeeding

   (Notes to trainers: Allow risk factors such as radiation from diagnostic tests and exposure to chemicals to be included on the list; however, be sure to clarify that heredity, for example, is a greater risk factor than radiation exposure from mammography.

   Also, it is important to note that having a physical limitation or other type of disability may be linked with some of the risk factors listed above. Having a disability can greatly influence a woman's options and decisions about diet, physical activity level, childbearing and breastfeeding. Lifestyle actions that are more prevalent among women with disabilities may also put them at increased risk of developing breast cancer.)

8. Go through the same process for the cervical cancer category.

	What are risk factors for cervical cancer? -Being a woman -Having human papilloma virus (HPV), a virus that is usually transmitted through sexual contact -Being sexually active -Having sex at an early age -Having several or more sexual partners -Having a sexual partner who has or has had several or more sexual partners -Not getting regular Pap smears -Smoking -Family history ♦ Women with disabilities often do not get regular Pap smears, in part because of the accessibility issues surrounding preventive health care. Also, because so much attention is focused on their chronic conditions, these women may deny the need for screening tests, and their physicians may fail to recommend them. Finally, one should not assume that women with disabilities are not sexually active. 9. Explain HPV. Include brochure on HPV, if available. ♦ The list of risk factors for cervical cancer includes several that have to do with sexual behavior. That is because the human papilloma virus (HPV), a virus that is usually transmitted through sex, is present in 99% of cervical cancer cases. HPV is extremely common. Many people have HPV, but don't know it because the virus usually has no symptoms and usually doesn't cause any problems. ♦ Some types of HPV can cause cells in a woman's cervix to grow abnormally and become cancer cells. It is important to remember, however, that although a lot of women have HPV, only a small percentage develop cervical cancer. ♦ HPV is the reason that sexual activity is a risk factor for cervical cancer. HPV is usually transmitted during sex. Since the virus is so common, everyone who has ever had sex is at some risk of having HPV. Using a condom may give a woman some protection from getting HPV. ♦ Having several or more sex partners throughout your life or having a partner who has had several or more partners increases a person's chance of HPV infection. Girls who have sex at an early age are at high risk for getting HPV because

their cervixes are still developing and more susceptible to infections.

- Any woman who is or has ever been sexually active may have been exposed to HPV, which puts her at risk for cervical cancer. Basically, just about all women are at risk for cervical cancer even if they are no longer sexually active or are in a monogamous relationship. Gardasil®, the 3-dose HPV vaccine developed by Merck, is close to 100% effective in preventing persistent infection and clinical disease associated with HPV type 6 & 11 (subtypes associated with 90% of all genital warts) and types 16 & 18 (subtypes associated with 70% of all cervical cancers, and many vulvar and vaginal cancers).

- The Food and Drug Administration (FDA) has licensed Gardasil® for use with females ages 9-26 for the prevention of cervical pre-cancer and cancers, vulval and vaginal pre-cancers, and genital warts.

- Merck has priced the series of shots at $360 ($120 per dose), but individual provider's offices may charge additional fees.
  http://www.ashastd.org/hpv/hpv_vaccines.cfm

10. Summarize activity by reading the final, correct list of risk factors for breast cancer and the list for cervical cancer. Pass around Handout #1C, Risk Factors.

    Discuss lists.

    - What information here is new or surprising to you?
    - What similarities are there between the two lists?
    - What about differences?
    - How do these lists make you feel?

11. Pass out Session 1 summary handout, Breast and Cervical Cancer: The Basics (#1D), to participants. Take a few minutes to review what it says so that women follow along on their own copies.

12. Lead into closing.

    - When talking about breast and cervical health, especially as LHAs, it is important to understand the human body. In our next session, we will learn more about women's bodies.

Trainer's Notes	

Closing/Evaluation

Trainers:

Time: 15 minutes

Background: The closing part of the training provides an opportunity to reflect on what was covered in the session and gather feedback on how to improve the session. Because of the large amount of information about breast and cervical cancer presented at each session, it is important to review and reinforce the distinctions and similarities between the two cancers. An assignment is also included in the curriculum to help participants apply what they learned in the session and to gather information for the next session.

Training Objectives:

At the end of this activity trainers will have:

1. Summarized the session activities.
2. Reviewed the similarities and differences between breast and cervical cancer.
3. Gathered feedback from the group about the session.
4. Encouraged participants to gather information that will be used in the next session.

Materials:

- Session 1 learning objectives
- Session 1 agenda
- Parking lot flipchart page
- Flipchart
- Markers
- Homework assignment handouts

Steps:

1. Introduce closing and evaluation.

    - ♦ We did a lot today. At the end of each session it is important to reflect on what we learned and to think about what worked and what did not. First, let's review what we covered today.

2. Summarize learning objectives.

- Today we…
  -Found out what the training was about,
  -Familiarized ourselves with the history of BCSP,
  -Talked about what makes a good LHA,
  -Heard why breast and cervical cancer are important health concerns,
  -Discussed risk factors for breast and cervical cancers.

3. Explain Pluses and Wishes. Draw a line down the middle of a flipchart page. Write "Pluses" on one side of the line and "Wishes" on the other side.

   - Now we want to talk about what worked and what did not during today's session. Pluses are things that you liked about the session. Wishes are things that you would like to be done differently at future sessions. Pluses and Wishes can be about any part of the training (content, food, temperature, activities, etc). After the list is complete, the training planners will meet to make changes that are possible and appropriate.

4. Ask the group to list some "pluses" first, and then "wishes." *(The trainer should not respond to the wishes, just record them).*

   - Thank you for all of your input. We appreciate your acknowledgement of the pluses and will try to address the wishes as best we can.

5. Review parking lot. Cross off items that were addressed. Acknowledge those that will be addressed in future sessions.

   - Were any of the parking lot items addressed? If so, they can be marked off the list.

6. Explain homework activity. Pass around Handout #1E, "Talking with a friend."

   - Each week between sessions, we are going to ask you to complete a brief activity. These activities will help you prepare for the next session. For next time, I'd like you to talk with at least one other woman who is not in this training about Pap screening and mammography.

   - As lay health advisors, you will be talking with a lot of women, sharing information and encouraging them to get screened for breast and cervical cancer. For this activity, though, I don't

want you to speak with them as lay health advisors. I just want you to ask them a few questions to learn about their experiences with Pap smears and mammography.

- Some women get screened regularly and some do not. Some women have good experiences and some have not-so-good experiences. I hope that you will take the time to talk with another woman before our next session about her experiences. The stories you hear will be helpful during the next session when we discuss early detection and the barriers to getting screened regularly.

- To help you with this assignment, we have a worksheet with questions you might ask and space to write down information. The questions to ask include:
  -Has she had a Pap smear or mammogram?
  -How often does she get Pap smears or mammograms?
  -What was the experience of getting a Pap smear or mammogram like?
  -If she hasn't had a Pap smear or mammogram, what are some of the reasons why?

- Some of you may be used to talking with other women about things like mammography and Pap smears, but it may be new for others. In fact, it may even feel a little embarrassing at first for some of you since Pap smears may not be a common thing to talk about. But, I want to encourage you to try and complete the assignment. You might want to start the conversation by telling her about this training or talk to someone you feel comfortable with like a sister, mother, best friend or aunt.

7. Close session with a prayer led by one of the participants *(if the group agreed at the beginning of the session).*

   - To bring our session to a close, who would like to lead us in a prayer?

8. Remind participants about the time, place, activities and assignment for the next session.

   - The next session is:
     Date:
     Time:
     Location:
   - We will talk in more detail about early detection, specifically Pap screening and mammography.

	♦ Remember to bring your notebook and note pad every week, as we'll continue to have handouts for you to take home. 9. Thank the group for coming. Acknowledge that you learned something from the participants. ♦ Thank you for your time and energy. Working together like this, we all come away with more knowledge about how to help women in the community have good health. I really enjoyed meeting all of you and hearing a little about each of you and your experiences. I look forward to learning more about you next time. 10. Leave the lead trainer's contact information on the flipchart in case the participants have any concerns or questions.

Breast Cancer
in Black and White Women

Women who got breast cancer in 2009
(out of 100,000)

African American women (117.7)

White women (127.8)

White women are more likely to get breast cancer…

Women who die from breast cancer
(out of 100,000)

African American women (33.0)

White women (23.9)

but African American women are more likely to die from it.

Source: SEER Cancer Statistics Review 2009, National Cancer Institute. http://seer.cancer.gov

Cervical Cancer
in Black and White Women

Women who got cervical cancer in 2009
(out of 100,000)

African American women (10.4)

White women (8.1)

African American women are more likely to get cervical cancer…

Women who die from cervical cancer
(out of 100,000)

African American women (4.6)

White women (2.2)

and are twice as likely to die from it.

Source: SEER Cancer Statistics Review 2009. National Cancer Institute.
http://seer.cancer.gov

What are risk factors for breast cancer?

Age (being older than 40)
Being a woman
Smoking
Mother, daughter, sister with breast cancer (Family History)
Never having children
Having first child after age 30
High fat diets
Being greatly overweight
Not breastfeeding

What are risk factors for cervical cancer?

Being a woman
Smoking
Family History Having HPV
Being sexually active
Having sex at an early age
Multiple sexual partners
Not getting regular Pap smears

What are Risk Factors for both breast and cervical cancer?

Being a woman
Smoking
Family History

Breast and Cervical Cancer: The Basics

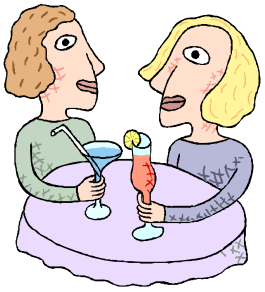
- Cancer occurs when cells in one part of the body grow without control or order.
- Over time, the cancer cells can spread to other parts of the body.
- Often breast and cervical cancer do not have any visible symptoms.
- Mammograms can detect breast cancer early – before a woman is able to notice any signs or symptoms.
- Pap smears detect abnormal cells and cancer cells in the cervix. In fact, Pap smears can find a problem before cancer develops.
- Mammograms and Pap smears save lives.

Breast Cancer

- The most important risk factor for breast cancer is age. As a woman ages, her risk of getting breast cancer increases.
- African American women are less likely than White women to get breast cancer.
- But, African American women are more likely to die from breast cancer compared to White women.

Cervical Cancer

- The most important risk factor for cervical cancer is human papillomavirus (HPV).
- HPV is very common. Many women have HPV and do not know it. It is usually passed through sexual contact.
- African American women in NC are 3 times more likely to die from cervical cancer compared to White women.
- Cervical cancer can be prevented.



Talking with a friend

Does she know it is important to have a routine Pap smear and mammogram?

_____
_____
_____

Has she had a Pap smear or mammogram?

_____
_____
_____

How often does she get Pap smears or mammograms?

_____
_____
_____

What was her experience of getting a Pap smear or mammogram like?

_____
_____
_____

If she hasn't had a Pap smear or mammogram, what are the reasons why?

_____
_____
_____

Breast & Cervical Health
Session 2

Agenda

- **Arrival/Gathering** (20 minutes)
- **Review/Preview** (10 minutes)
- **Warm-Up: Apples & Oranges** (5 minutes)
- **Anatomy & Early Detection: Mammography & Pap Smears** (70 minutes)
- **Breast & Cervical Cancer: All on the Wall** (20 minutes)
- **Barriers to Mammography & Pap Screening** (40 minutes)
- **Closing/Evaluation** (20 minutes)

Learning Objectives

- **Learn about female anatomy**
- **Find out about early detection for breast and cervical cancers**
- **Discuss reasons why some women don't get regular mammograms and Pap smears**
- **Understand ways to help women overcome barriers to early detection**

Total Time

3 hours, plus 10-minute break

Handouts

- **Breast anatomy (#2A)**
- **Mammography machine (#2B)**
- **Female reproductive anatomy (#2C)**
- **Supportive Communication (#2D)**
- **Session 2 summary (Finding Breast & Cervical Cancer Early -- #2E)**

Flipchart templates

- **Session 2 learning objectives**
- **Session 2 agenda**
- **Diagram of breast anatomy**
- **Diagram of reproductive anatomy**
- **Role play questions**

Trainer's Notes	

Arrival/Gathering

Trainers:

Time: 20 minutes

Background: The workshop incorporates 20 minutes for arrival, sign-in, and gathering. At the end of the 20 minutes, participants should be gathered at the table and ready to begin the workshop.

Training Objectives:

At the end of this activity trainers will have:
1. Completed logistical aspects of the workshop.

Materials:

- Name tags
- Pens
- Sign-in sheet
- Refreshments

Steps:

1. Make sure the room is set up before participants begin arriving.
2. Have person(s) greet participants as they arrive.
3. Have table with registration materials clearly displayed. Have all participants sign in and put on name tags when they arrive.
4. Encourage participants to eat and mingle.
5. Inform participants 5 minutes before the start of the session activities so they can begin gathering at the table.

Trainer's Notes	

Review/Preview

Trainers:

Time: 10 minutes

Training Objectives:

At the end of this activity trainers will have:

1. Started the workshop with a safe and comfortable atmosphere.
2. Reviewed the ground rules and added to them if necessary.
3. Reviewed and addressed wishes from Session 1.
4. Summarized what was covered in Session 1.
5. Addressed any questions or concerns regarding Session 1 material.
6. Introduced agenda and learning objectives for Session 2.

Materials:

- Ground rules
- Parking lot
- Pluses and wishes from Session 1
- Session 1 learning objectives
- Session 2 agenda
- Session 2 learning objectives

Steps:

1. After everyone is seated welcome them to the session. Acknowledge any new observers, guest trainers, etc.

2. Open the session with a prayer led by one of the participants.

    - ♦ As we did last time, I'd like to open this session with a prayer. Today _____ is going to lead us in the opening prayer.

3. Remind participants of the ground rules that were created in the first session. (The list should be posted in the room where everyone can see them). Have a participant read the list aloud to the group. Ask the group if they have any questions, changes, or additions to make to the list.

4. Post Pluses and Wishes from previous session. Acknowledge the pluses and explain which Wishes were addressed and how.

    - ♦ I appreciate the feedback you gave about the last session.

	These are some of the things that people liked about that session...(list a few pluses). ♦ Some of the suggestions that were made for improving the session were…(list wishes). We could accommodate these requests (list) by doing (…). However, these requests were beyond the scope of the workshop. ♦ Thank you again for the feedback. We tried to address as many as possible to meet your needs. 5. Review learning objectives from Session 1. Ask if anyone has any questions or concerns from the previous session. ♦ Let's take a look back at what we did last session. Last session we…(read learning objectives). Does anyone have any questions about information or activities from last time? 6. Review the Session 2 agenda and learning objectives. Post on wall. ♦ Now let's look at what we're going to do today. 7. Acknowledge parking lot. ♦ As promised, the parking lot is back to keep track of concerns that come up which we cannot address immediately. We will mark off items as they are discussed. 8. Lead into next activity. ♦ Since this is only our second time meeting together as a group, we want to spend the next few minutes getting to know each other a little better.

Trainer's Notes	

Warm-Up: Apples and Oranges

Trainers:

Time: 5 minutes

Background: This activity provides an opportunity for participants to get to know each other better, while reestablishing the safe and comfortable learning environment. Further, the trainer seeks to connect the idea of "apples and oranges," how the women are alike and different from each other, with breast and cervical cancer. This serves to reinforce the preceding review.

Training Objectives:

At the end of this activity trainers will have:
1. Continued to build trust among workshop members.
2. Provided an opportunity for participants to learn more about each other.

Materials:

None

Steps:

1. Introduce activity.

   - This is a fun activity to get to know each other better. There is a saying about comparing apples and oranges. Who's ever heard the phrase "comparing apples and oranges?" *(Trainer pauses for a show of hands from the participants)*

   - Can anyone explain it?

   Trainer should call on one or two group members to explain what they thing the phrase means. Depending on the response of the group members, the trainer can reaffirm the explanation with how the apple/orange are the same and how they are different. Then take the explanation one step farther to include comparing breast and cervical cancer- in some ways they are the same and some ways different.

2. Explain activity.

	♦ We're going to go around the room, now, and I want each one of you, when it's your turn, to give us your name and one piece of information that *you think* makes you similar or different from the other ladies here. For instance, you might share where you were born, or an activity that you enjoy doing in your spare time. *Note to trainer: let women go around the room, introducing themselves. Try to keep a few threads throughout the discussion – if women start to contrast where they grew up, or which elementary school they went to, or that they like cook. This will help you reinforce the metaphor to breast and cervical cancer in the next step.* 3. Bring group back together. ♦ As you can see from our introductions, we have many ways in which we are similar and different. It's the same way with breast and cervical cancer. The two diseases share many characteristics, including the lack of symptoms and the ability to detect them in an early stage. They also differ in many respects: they affect different parts of the female body and they have different risk factors. 4. Lead into the next activity. ♦ I hope this activity helped you learn more about each other. As we are learning, these two cancers also have many similarities and differences. Now let's turn our attention to the topics of female anatomy and early detection.

Trainer's Notes	

Anatomy and Early Detection: Mammography and Pap Smears

Trainers:

Time: 70 minutes

Background: The purposes of this activity are: (a) to familiarize participants with female anatomy, so it is understood where breast and cervical cancers occur in a woman; and (b) to present detailed information about early detection of breast and cervical cancers. Trainers should build upon participants' levels of knowledge, encourage questions, and clarify as necessary.

Training Objectives:

At the end of this activity trainers will have:

1. Reviewed female anatomy.
2. Provided an opportunity for participants to ask questions about female anatomy.
3. Encouraged participants to apply their knowledge of female anatomy.
4. Presented information about mammography.
5. Presented information about Pap smears.
6. Distinguished between pelvic exams and Pap smears.
7. Defined screening guidelines for mammography and Pap screening.
8. Provided a visual example of a Pap smear procedure.
9. Introduced medical instruments and other visual aids related to mammography and Pap screening procedures.

Materials:

- Large diagram of female breast and reproductive anatomy (internal and external organs)
- Pens
- Labeled anatomy diagrams for participants (including internal and external organs) Handouts #2A & #2C
- Breast models
- Bead necklaces, including those for LHAs
- Mammography films
- Mammography machine handout (#2B)
- Speculum
- Cytobrush
- Spatula
- Glass slide
- Pap smear video
- TV

- VCR

Steps:

1. Introduce activity and acknowledge that it may be embarrassing or difficult for some people to talk about sexual organs.

   - ♦ Since we are learning about female cancers, it is important to understand female anatomy. Because most of our female organs are inside our bodies, we aren't able to see them. Because of this, many women don't know very much about their bodies.

   - ♦ It may be uncommon for women to discuss their bodies or sexual organs. For that reason, it may be difficult or embarrassing for some people to talk about it, especially in a group.

   - ♦ It is ok to feel embarrassed. But, I hope we all respect our ground rules so that everyone here feels safe learning and asking questions about female anatomy and our reproductive organs.

BREAST ANATOMY & DETECTION

2. Present mini-lecture on Breast Anatomy. Post a large diagram of female breast (sagotta section view) and point out each structure as it is described. *(Pass out handout of breast anatomy #2A.)*

INTERNAL

CHEST WALL

- ♦ Ribs, intercostals space (muscles, nerves and blood vessels), pectoris major (chest muscles).

FATTY TISSUE and CONNECTIVE TISSUE

- ♦ Fatty tissue is what makes our breasts different sizes. Different women are genetically programmed to carry different amounts of fatty tissue in their breasts. Connective tissue are ligaments that hold our breasts up against the chest wall. These ligaments are strong and firm in young women, but get strained by the weight of the breast as we age.

LOBES & LOBULES

- Each breast has 15 to 20 lobes or small compartments. Each lobe/compartment has smaller lobules. Lobules are lined with milk secreting cells called alveoli.

MAMMARY DUCTS

- Mammary ducts transport milk from lobules to storage ducts called AMPULLE. From the ampulle duct, milk is secreted through LACTIFEROUS DUCTS to the NIPPLE.

- Changes in lobes, lobules, and ducts are influenced by hormones. When the body is pregnant, the alveoli produce milk. Even when not pregnant, each month in harmony with the menstrual cycle the breast undergoes changes including increased blood flow, retention of fluid and enlargment of the lobules. After the menstrual period the breast structures return to normal size. This is one reason to schedule mammograms for the 1 or 2 week after a period for women who are menstruating.

EXTERNAL

NIPPLE and AREOLA

- The nipple is the most prominent feature of the external breast anatomy. The nipple is surrounded by rough looking tissue called AREOLA.

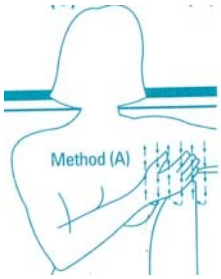
3. Introduce information about mammography, Breast self exam and clinical breast exam. Using a lecture format, provide the information while allowing for participants to include their thoughts as applicable. And they probably will, because our LHAs don't seem to have a problem saying what's on their minds. Follow up with corrections as necessary. As descriptions of the procedures are presented, pass around visual aids to help clarify information. Begin with mammography information.

MAMMOGRAPHY

- Let's start off talking about mammography. Who here hasn't had a mammogram? Can some of you who have had mammograms please share one positive comment about your experiences?

- So what is a mammogram, exactly? It is an x-ray of the breast. It can find tumors too small to be felt and can show other changes in the breast that may suggest cancer. A mammogram usually consists of two x-rays of each breast taken from different angles. This is what a mammogram x-ray film looks like. *(Pass around mammography films.)*

	♦ Getting a mammogram is important because the earlier a breast cancer lump is found, the easier it is to treat and get out all the cancer. Mammograms are the best way to find a breast lump or notice changes in the breast early. ♦ Sometimes women experience some discomfort when getting a mammogram. Can anyone who has had a mammogram share with us ways you have positively influenced your experience with this? *Note to Faciliiator: Methods such as taking a pain reliever before the mammogram, practicing relaxation techniques, or talking to the technician could be discussed.* ♦ This is what happens during a mammogram procedure: Before the mammogram, you remove your clothing from the waist up and are asked to place one breast on a small platform. Then, the breast is compressed by a device called a paddle, which is lowered onto the breast from above. With your breast squeezed between the platform and paddle, you hold your breath, the x-ray picture is taken, and the paddle is immediately released. The breast is then repositioned, the paddle is lowered, and another picture is taken. This procedure is then repeated on the other breast. (*Pass out handout with picture of mammography machine #2B.*) ♦ Some women require a modified procedure if they are in a wheelchair or otherwise unable to stand at the machine. A woman with disabilities may need assistance or extra time undressing, for instance. It is always a good idea for women with such limitations to ask, when they schedule their appointment, if the facility can accommodate their special needs. ♦ <u>So who should get mammograms?</u> Women age 50 and older should have a mammogram every year. Women age 40-49 should get one every 1-2 years. Women also can get a baseline mammogram, which is their first mammogram that is used to compare with later mammograms, at age 35, or as recommended by their doctor. Women with disabilities should follow these same guidelines, unless instructed otherwise by their physician. Women with a family history of breast cancer should ask their doctor when they should begin having mammograms; they may need to start getting mammograms at an earlier age. ♦ Different women can have different screening recommendations depending on their specific situations. It is important to talk to your provider to find out what is best for you.



Demonstrate breast self-exam using breast model.

CLINICAL BREAST EXAMINATION

- There are other ways that some breast lumps can be detected, and these should be part of our regular preventive health efforts:

- During a clinical breast exam, the nurse or doctor feels the breast and underarm with the fingers to check for lumps and other changes. Women should have a clinical breast exam with each routine check-up or annual gynecological exam. Women with mobility impairments may be forced to put off routine check-ups.if they cannot find a facility with a wheelchair accessible exam table.

BREAST SELF-EXAMINATION

- A breast self-exam is similar to a clinical breast exam but in this case a woman is feeling her own breasts and underarms to check for lumps or other changes. Women should do a breast self-examination once a month to become familiar with the usual appearance and feel of her own breasts.

  A breast self exam has two parts: **Looking** and **Feeling**.

  Looking.
  Stand in front of a mirror and look at your breasts. No one's breast are both exactly the same. Look for anything unusual: puckering, discharge, changes in color or shape. 3 poses:

  - Arms hanging at your sides
  - Hands over your head
  - Hands on hips, shoulders rolled forward.

  Feeling.
  - While **standing,** feel each breast, one at a time: 3 fingers, 3 circles, 3 pressures. Using the flat part of three fingers, begin in your armpit. Press gently in a small circular motion – pressing lightly, medium and deeply. Feel through the entire thickness of the breast. Move the fingers down slightly and repeat 3 circles, 3 pressures. Continue to move your fingers down so you cover the entire area from your collar bone to your bra line and from arm pit to chest bone.

  - **Laying down,** repeat the same 3 fingers, 3 circles, 3 pressures while laying on your back. Examine the entire breast from arm pit to chest bone; collar bone to bra line.

  - Women with self-care limitations, or less dexterity and upper

Notes to trainer:
Pass around breast models and encourage women to try and find the lumps in them. This is most productive if supervised in a guided practice format, where the trainer leads each woman, one at a time, through the examination of the model until she feels a lump.

If more than 6-8 women, use additional models and trainers for guided practice.

extremity range of motion, may be unable to perform BSE as we've described it. They should ask their health care provider about ways to compensate.

- Now we are going to practice the technique for doing a breast self-examination using a breast model. This model has different size lumps in it, so we will see how much pressure we must use to feel them. *(See trainer notes in margin.)*

- Your health care provider may use a different exam technique such as examining the breast in circles. Although different techniques exist, they all do the same thing, check for changes.

- A monthly breast self-examination can help a woman notice any changes that occur with her breasts. If a woman does notice changes, it's important for her to see her health care provider about it.

- Remember, though, there are some changes or lumps that develop in women's breasts that cannot be detected by touch. And, not all lumps mean that a woman has breast cancer. A mammogram is the only way to find changes in the breast that are too small to be felt and the only way to know if changes in the breast are cancerous.

4. Introduce the beaded necklace. Pass out enough beaded necklaces so that each participant receives one to keep.

   - To demonstrate how breast self-exam, clinical breast exam, and mammography can all be used to detect changes in a woman's breast, we have a special teaching tool—the beaded necklace. Many of our current LHAs use this necklace to help educate other women about early detection of breast cancer.

   - The beaded necklace shows the size of the lump that might be found by the different types of detection procedures. For example, a lump this size (point to largest bead) might be found by a woman who rarely examines her own breasts. (Continue with all beads, using the reference card to describe each size.)

5. Ask if any current LHA wants to share one experience of how she's used the beaded necklace to educate women in her community. Thank the LHA and proceed.

- ♦ Of course, you might want to use it in other ways. The reference card shows what you need to know in regard to each size of bead.

6. Lead into discussion about signs and symptoms.

   - ♦ The number one thing we can do to lower our risk of dying from breast cancer is to get a regular mammogram.

   - ♦ Other than having a mammogram, how can a woman tell if she has breast cancer?

   (She has a lump, an inverted nipple, nipple discharge, dimpling of the skin or skin that looks like an orange peel. These are possible signs of breast cancer, but not definite ways of knowing.)

7. Emphasize the asymptomatic nature of the disease.

   - ♦ While these are possible signs of breast cancer, in many cases there are <u>no</u> visible signs or symptoms. In fact, by the time there are symptoms, the cancer is often very advanced and more difficult to treat. Just because we feel fine doesn't always mean that there is nothing wrong. The best way to protect yourself from breast cancer is to have a mammogram. And because cancer can develop slowly over time or suddenly, even after you get a mammogram, it's important to get them on a regular basis.

8. Emphasize that mammography is the MOST important detection tool, then CBE, and lastly BSE because of the size of the lumps that can be felt with BSE.

<u>CERVICAL ANATOMY & SCREENING</u>

9. Continue with lecture format to introduce reproductive anatomy. Post a large diagram of reproductive anatomy and point out each structure as it is described. *(Pass out reproductive anatomy handout #2C.)*

   <u>UTERUS</u>

   - ♦ Can someone tell me the name of the organ where our period comes from or where a baby develops during pregnancy?

   - ♦ What are some of the other names that the uterus is called? The uterus is a small muscular organ about the size of a fist. Each month when a woman has her period, the lining of the uterus is

shed.

CERVIX

- The bottom end of the uterus is called the cervix. It feels a little like the tip of your nose. (Touch your nose). It is here where cervical cancer can develop.

OS

- The opening through which blood flows during menstruation is the os. It expands when we go through childbirth to let the baby pass from the uterus to the vagina.

VAGINA

- The cervix is at the end of this passageway. Who can tell me what this passageway is called? (Vagina).

- The vagina is the entrance inside a woman's body. Blood passes through the vagina during our period and babies pass through during childbirth. It is also the place where a man inserts his penis during vaginal sex. This is where tampons are inserted. It is also where the health care provider inserts an instrument called a speculum, so that he or she can see the cervix during a Pap smear.

OVARIES

- Who can tell me what these are? (Point to ovaries). The ovaries make eggs and female hormones. In women who haven't reached menopause, each month the ovaries release an egg that travels into the uterus.

FALLOPIAN TUBES

- The tubes that carry the egg from the ovaries to the uterus are the Fallopian tubes.

10. Ask for questions.

    - Does anyone have any questions so far?

11. Clarify what it means to have a hysterectomy.

    - Now that we are more oriented with our bodies, who can tell me what happens to a woman's anatomy when she has a hysterectomy?

    - There are basically three types of hysterectomies. A partial hysterectomy is removal of just the upper portion of the uterus,

The trainer can demonstrate these steps by using her fist. Pretend curled pointer finger is the cervix. Use spatula to collect cells around the outside of the cervix and the cytobrush to collect cells inside the cervical opening	leaving the cervix and the base of the uterus intact. A total hysterectomy is removal of the entire uterus and cervix. A radical hysterectomy is the removal of the uterus, cervix, Fallopian tubes, ovaries, and the upper part of the vagina. ♦ It is important for a woman who has had a hysterectomy to know what type she has had, so she knows if she is still at risk for cervical cancer. A woman who has had her cervix removed cannot develop cervical cancer; however, a woman who has had a partial hysterectomy and still has cervix may be at risk for cervical cancer. 12. Introduce Pap screening information. ♦ Now let's talk about early detection for cervical cancer. A Pap smear is an examination of the cervix to look for cancer or any changes in the cells that may lead to cancer. Remember from our anatomy lesson that the cervix is the opening to the uterus. ♦ Getting a Pap smear is important because it is the only way to tell if a woman has cervical cancer. It can also detect changes in the cervical cells that may lead to cancer, and allow a woman and her doctor to take steps to prevent it. **Cervical cancer is unique in that it is almost totally preventable and treatable if found early**. ♦ During a Pap smear, a woman lies down on her back on the exam table and puts her feet in the stirrups. The doctor or nurse then inserts a speculum into her vagina in order to see into the vagina. (*Show speculum and pass it around*). The speculum is lubricated and may be uncomfortable, but it should not hurt. The doctor or nurse then uses a tiny brush called a cytobrush to take a few cells from inside of the cervix. They will also use an instrument called a spatula to take a few cells from outside of the cervix. The doctor or nurse then smears the cells collected by the cytobrush and spatula onto a glass slide. The slide is then sent to a laboratory and the cells are checked for cancer or other problems. (*After demonstration, pass around cytobrush, spatula, and slide*). ♦ All females should begin getting Pap smears when they turn 18 years of age or when they become sexually active, whichever comes first.

- When thinking about how often you should get a Pap smear, in general, it is recommended that a woman get a Pap smear once a year. However, if a woman has three normal Pap smears in a row, her doctor or nurse may recommend that she get one less often. On the other hand, if a woman has an abnormal Pap smear, her doctor or nurse may recommend that she get one more often than just once a year.

- Even women who have had a hysterectomy may need a Pap smear, depending on their cancer history and whether their cervix is intact. Any woman who has had a hysterectomy MUST talk to her health care provider about her specific situation and find out what is best for her.

- Again, women with disabilities should follow these same guidelines. For example, when talking to a woman with developmental disabilities, do not assume that she isn't sexually active and therefore does not require an annual Pap smear.

- What is a pelvic exam? A pelvic exam is when a doctor or nurse uses their hands to feel a woman's reproductive organs, including her fallopian tubes, ovaries, and uterus, to see if they feel anything abnormal.

- How is a Pap smear different from a pelvic exam? A Pap smear is usually part of a pelvic exam, but the Pap smear is just the part where the doctor or nurse collects cells from the cervix. During the rest of the pelvic exam, the doctor or nurse feels a woman's fallopian tubes, ovaries, and uterus for any lumps or tenderness. It is possible to have a pelvic exam without a Pap smear. But, if a woman gets a Pap smear, it will be during a pelvic exam. It is important to always ask your health care provider if you are getting both a Pap smear and a pelvic exam.

- Remember, even women who've had a hysterectomy need regular pelvic exams and they may need a Pap smear as well. When a woman goes in for a Pap smear and pelvic exam, often called an annual gynecological exam, the doctor or nurse will often also perform the clinical breast exam.

13. Show video demonstrating the Pap smear procedure.

- To help demonstrate exactly what happens during a Pap smear,

	we have a video that shows a woman receiving a Pap smear. It lasts about _____ minutes. 14. Discuss video. ♦ What did you see in the video that was interesting or surprising? ♦ What information in the video was new information for you? 15. Discuss signs and symptoms of cervical cancer. ♦ The number one thing we can do to lower our risk of dying from cervical cancer is to get regular Pap smears. ♦ Other than a Pap smear, how can a woman tell if she has cervical cancer? *(Abnormal bleeding or abnormal vaginal discharge may be signs of cervical cancer, but not necessarily. They may also be signs of something else. A Pap smear is the only way to know if she has cervical cancer.)* 16. Emphasize asymptomatic nature of cervical cancer. ♦ Remember, just as with breast cancer, in many cases of cervical cancer, there may be <u>no</u> visible signs or symptoms. By the time there are symptoms, the cancer is often very advanced and harder to treat. The best way to protect yourself from cervical cancer is still to have Pap smears on a regular basis. 17. Encourage participants to share their own experiences getting a Pap smear or mammogram. ♦ For those of you who have had a mammogram or Pap smear, what was the experience like for you? ♦ How did you feel after it was over? ♦ For those of you who did the homework activity, what did you learn about other women's experiences getting mammograms and Pap smears? 18. Wrap up discussion and clarify any concerns or questions.

	♦ As lay health advisors, it's important to be aware that different women have different experiences getting mammograms and Pap smears. Some have good experiences and some have not-so-good experiences. As we will later discuss, it will be important to understand how women feel about Pap smears and mammograms when we're advising them. ♦ We have covered a lot of information so far today. Are there any questions at this point? 19. Lead into next activity. ♦ The next activity we do will help summarize and reinforce all the information we've covered so far about breast and cervical cancers. But, first let's take a 10-minute break. *Note to trainer: During the break, ask some of the more outgoing participants if they would be willing to act out one of the character scenarios in a later activity.*

B R E A K

Trainer's Notes	

Breast and Cervical Cancer: All on the Wall

Trainers:

Time: 20 minutes

Background: This activity provides an opportunity to summarize and review all the key messages that have been delivered so far regarding breast and cervical cancers.

Training Objectives:

At the end of this activity trainers will have:

1. Summarized the key messages presented so far regarding breast and cervical cancers.
2. Clarified any questions or misperceptions about information related to risk factors and early detection.
3. Emphasized the similarities and differences between the two cancers.

Materials:

- Sentence strips prepared with statements about breast and cervical cancers.
- ½ sheets labeled with the following categories: "Breast cancer and mammography," "Cervical cancer and Pap screening," and "Both"

Steps:

1. Introduce activity.

    - ♦ We have covered a lot of information in a short amount of time about breast and cervical cancers. This activity will give us an opportunity to review the key messages in that information and clarify any questions we have so far. For this next activity, you might want to look at your handout from session 1 on cancer risk factors.

2. Explain activity. Post categories on sticky wall.

    - ♦ On the sticky wall we have three different categories: Breast cancer and mammography, cervical cancer and Pap screening, and both.

    - ♦ Each one of these sentence strips has a statement that belongs in one of those categories. I would like each person to take a

	sentence strip, read what the strip says, and then place it on the sticky wall under its appropriate category. If you're not sure where your strip belongs you can ask the group for help. ♦ After you put your strip in its category, please explain why you chose the category that you did. Again, feel free to ask the group to help explain. <u>Breast Cancer and Mammography</u> -African American women are less likely to get it, but more likely to die from it than White women -It is more common in older women than younger women -Women age 40-49 should start getting one every 1-2 years -Women age 50 should start getting one every year <u>Cervical Cancer and Pap screening</u> -African American women are more likely to get it and more likely to die from it than White women -HPV is a risk factor -All women should begin getting them when they turn 18 or become sexually active -All women should get one even if they are not sexually active <u>Both Cervical and Breast Cancers/Mammography and Paps</u> -It can be detected early -It can be treated -Family history is a risk factor -A woman can have it and not know it because there might not be any symptoms -A woman should get one even if she feels healthy 3. Pass out sentence strips and begin activity. Ask for volunteers to put their strips up one at a time. 4. As participants explain their statement and its category, check in with the group to see if they agree with or have questions about where each participant placed her sentence strip. Add information or correct misinformation as necessary. 5. Continue activity until all sentence strips are on the sticky wall and in the correct categories. 6. Lead into next activity. ♦ Great job everyone! I hope that was a good review for you and that you're starting to feel comfortable with all of this

	information. Now that we're convinced how important it is for women to get regular mammograms and Pap smears, we need to talk about some of the reasons women might not get them and how we can help them overcome those barriers.

Trainer's Notes	

Barriers to Mammography and Pap Screening

Trainers:

Time: 40 minutes

Background: This section of the training is designed to alert participants to some of the reasons why women don't get mammograms and Pap smears regularly. The character scenarios are designed to reflect women who face different barriers to screening and, therefore, are in different stages of readiness for engaging in screening. The character scenarios will prepare participants for the next session, in which they will develop advising skills based on TTM theory.

Training Objectives:

At the end of this activity trainers will have:

1. Raised participants' awareness about the barriers women face to obtaining mammograms and Pap smears.
2. Initiated discussion about how different barriers place women at different stages of readiness to change.

Materials:

- Flipchart
- Markers
- Colored sticks for dividing participants into two groups
- Role plays
- Supportive Communication handout (#2D)

Steps:

1. Introduce activity.

    ♦ As we discussed, it is important for women to get regular mammograms and Pap smears. Yet, some women don't get them as often as they should, and some don't get them at all. Some women might do one and not the other, and some might not do either. In this activity, we want to discuss some of the reasons why women don't get regular mammograms and Pap smears.

2. Explain activity.

- To do this activity, we are going to divide into two groups. Each group is going to get a flipchart page and markers. One group is going to brainstorm reasons why some women don't get Pap smears and the other group is going to brainstorm reasons why some women don't get mammograms. I want one person from each group to write down all the reasons your group comes up with on the flipchart page. You may also want to think about your "out-of-class" interview from last time. If you spoke with a woman hasn't had a mammogram or Pap smear, what were some of her reasons why? You will have about 5 minutes to brainstorm your lists.

3. Divide participants into two groups using colored sticks.

4. After 5 minutes, sound chime to bring attention back to larger group.

5. Ask one person from each group to post their flipchart page and present the group's list of barriers. Make sure participants clarify any barriers that are unclear to the group. Some common responses may include:
   -fear of finding cancer
   -cost
   -time
   -transportation
   -embarrassment
   -gender of health care provider
   -lack of knowledge
   -discomfort/pain
   -not having any symptoms
   -not having a doctor's recommendation
   -fear of radiation

(Note to trainer: if any barriers from this list are not mentioned by participants, ask if they feel like they are barriers that should be added to their lists.)

6. Discuss the barriers, comparing the similarities and differences between the lists for mammography and Pap screening.

   - What similarities do you see between the two lists? What barriers might be the same for both mammography and Pap screening? *(Mark the items that are similar on both lists with a colored marker so it is easier to see the remaining differences.)*

   - How are the two lists different? What barriers are unique to

Pap screening? What barriers are unique to mammography?

- Why might some people participate in one screening procedure, but not the other?

(Note to trainer: Ask open-ended questions that will encourage participants to address barriers that might be related to disability: For a woman with any sort of disability, what would be some reasons she might not be screened for cervical cancer? What about breast cancer?)

7. Summarize discussion and begin to tie in TTM concepts.

   - As we can see from this discussion and these lists, women can have many reasons for not getting a mammogram or a Pap smear. And, the barriers a woman faces to Pap screening may be different from the barriers she faces to mammography. As lay health advisors, it will be important to understand the reasons why women don't get mammograms and Pap smears, so that we can help them to overcome them. Obviously, depending on the reasons of each woman, some women may be more ready to get a mammogram or a Pap smear than others. We will talk more about how we can be the most effective in helping women overcome barriers in the next session.

8. Lead into activity on overcoming barriers.

   - For now, we're going to begin thinking about how these reasons we've listed for not getting mammograms and Pap smears might affect women in real life. To begin thinking about how we might help women, we are going to do an activity using character scenarios, or skits.

   - (Name volunteers) have agreed to test out their acting skills and play different characters. Each character will have a reason for not getting a mammogram or Pap smear.

9. Have volunteers read aloud the following scenarios one at a time. After each scenario, have participants assess what happened in that particular scenario. It is important for participants **not to discuss what they would do in each scenario,** but rather to recognize what barrier is presented in each scenario and what the LHA did. Use the following discussion questions after each scenario is acted out:

   - How did _____feel about getting a mammogram / Pap

smear?

- Why didn't she want to get a mammogram/ Pap smear?
- How did the LHA respond to her situation?

(Note to trainer: These scenarios are based on TTM concepts and designed so that different characters reflect different stages of readiness to change. This activity will begin to introduce how women in different stages receive different advice. It is helpful here to post the above three questions on a flipchart so that participants can refer back to them as they contemplate the scenarios.)

Character Scenarios

Character Scenario 1: No way Nora

LHA: Hi Nora, how you doin'?

Nora: What are you doing out here?

LHA: I'm talking about mammograms.

Nora: I don't want to hear anything about that. Isn't that about cancer? Now, why would I want to know if I have cancer? That's like telling me I'm going to die. I'd rather not know. I'm not interested, no way.

LHA: Well, Nora, I can see why you might not want to find out you have cancer, but the great thing about mammography is that it can find breast cancer early, while it can still be treated. So, even if you had cancer, it would be better to know so that you could get treatment. Mammograms actually save women's lives! Maybe, you could at least think about getting a mammogram?

Nora: Mmm, I'll think about it, but I don't think that's for me.

LHA: Just think about it. We'll talk again soon.

Character Scenario 2: Embarrassed Ethel

LHA: Hey Ethel, it's so good to see you! Now, you know I volunteer with Save Our Sisters, so I want to ask you something. Have you gotten your Pap smear?

Ethel: Oh, no I haven't. Listen, I know I need to get one, but I just can't. I mean, it so embarrassing. I don't want some other man touching my

private parts…it feels disgraceful to me.

LHA: Well, let's think about what might make it less embarrassing. You know, even if a man is performing the procedure, a woman, probably a nurse, will always be in the room. Or, I'd be happy to go with you if it would make you feel more comfortable. But, remember that doctors and nurses are professionals. They perform this test on women all the time because they want women to be healthy. Your health is more important than feeling embarrassed for a few minutes. The Pap smear is the only way to detect cervical cancer early while it can still be treated.

Ethel: I know, you're right.

LHA: Can I help you make that appointment now?

Ethel: Yes. Let's go.

Character Scenario 3: Why-Should-I Wendy

LHA: Hi, Wendy! I'm glad to see you out-and-about again. How are you doing?

Wendy: I'm better. Thanks for bringing that dinner by for Frank and the kids when I was sick. What are you up to these days?

LHA: Well, we're out here at the post office today reminding women about the importance of mammograms. Have you had a mammogram, Wendy?

Wendy: No, and I'm not sure I need to. I see several different doctors for all the problems I have and none of them has ever suggested that I might need one. They probably realize I already spend half my life at the clinic anyway! I sure don't need to make more appointments than I already need.

LHA: Yes, I can understand why you might not want to have to go to the doctor's office for another visit, but taking a mammogram can find breast cancer when it can still be treated. And we're both at an age when it's important to get screened every year. Maybe I could help you look into scheduling a mammogram on the same day as one of your other appointments at the clinic…

10. Thank the actresses and take them out of their roles.

    - ♦ Thank you _____. Now you can return to being _____ (participant's real name).

	11. Pass out the Supportive Communication handout (#2D), and tie it to role plays by suggesting some of the things you saw various "LHAs" doing to demonstrate their supportiveness. Emphasize careful listening as an important skill of an LHA. ♦ With these role plays, you may have noticed that some of you naturally used different techniques to make the person you were advising feel comfortable talking to you. For example, many of you made eye contact with your advisee as you were talking to her. What were some of the other techniques you saw? ♦ As lay health advisors, it's important to make women feel as comfortable as possible talking to you about breast cancer and mammography. This means being a supportive communicator. Most of you already do this naturally; but, just to reinforce what some of the techniques of a supportive communicator are, we summarized them on this hand-out. 12. Lead into next activity. ♦ We talked about a lot of the reasons women don't get mammograms or Pap smears. At the next session, we will spend time learning what we can do to help those women. Right now, however, it's time to draw this session to a close.

Trainer's Notes	

Closing/Evaluation

Trainers:

Time: 20 minutes

Background: The closing part of the training provides an opportunity to reflect on what was covered in the session and gather feedback on how to improve the session. Because of the large amount of information about breast and cervical cancer presented at each session, it is important to review and reinforce the distinctions and similarities between the two cancers. An assignment is also included in the curriculum to help participants apply what they learned in the session and to gather information for the next session.

Training Objectives:

At the end of this activity trainers will have:

1. Summarized the session activities.
2. Gathered feedback from the group about the session.
3. Encouraged participants to gather information that will be used in the next session.

Materials:

- Session 2 learning objectives
- Session 2 agenda
- Parking lot
- Flipchart
- Markers
- Session 2 summary handout (#2E)

Steps:

1. Introduce closing and evaluation.

    ♦ We did a lot today. Let's review what we covered today.

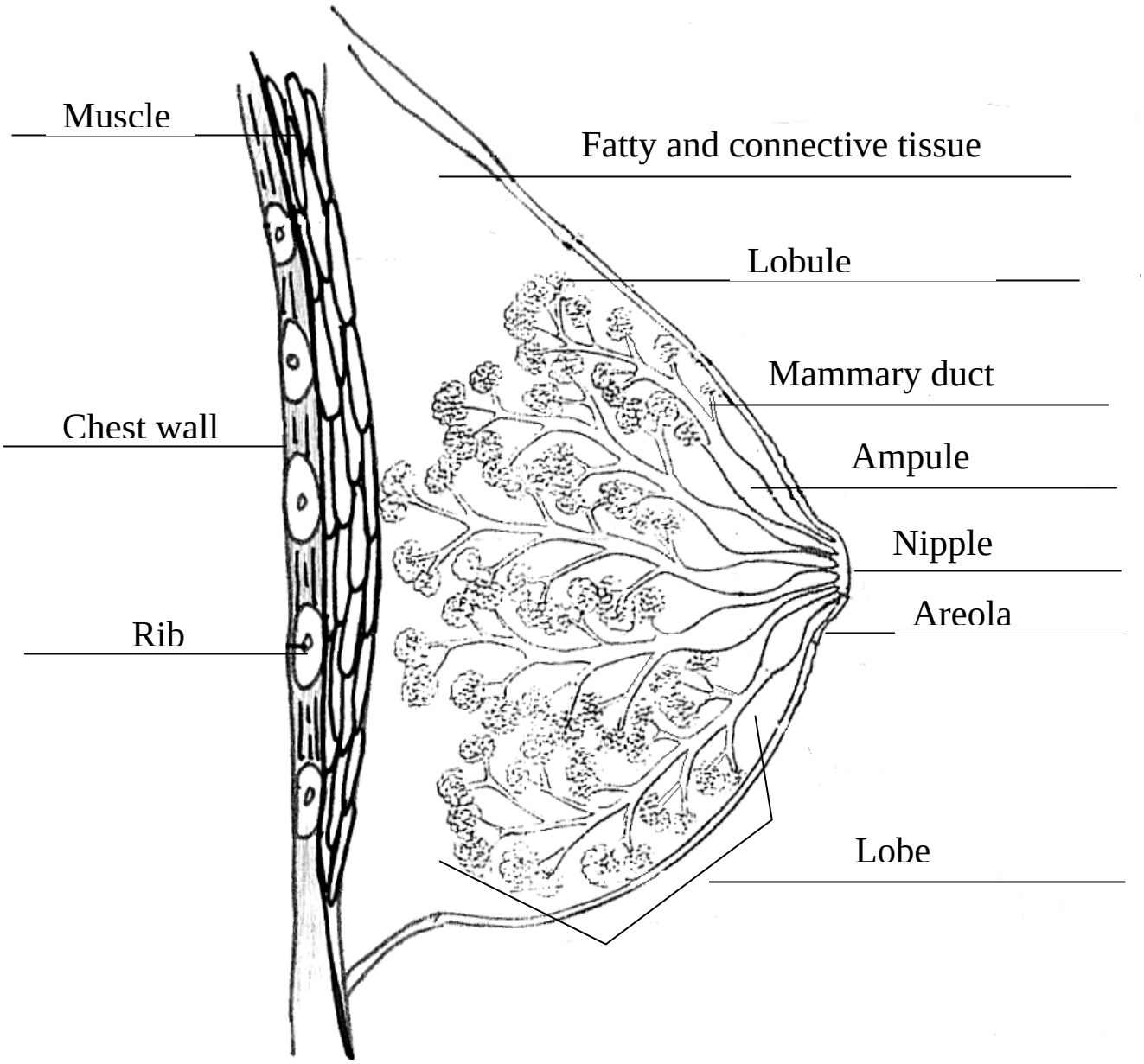
2. Summarize learning objectives.

    ♦ Today we…
    - Learned about female anatomy
    - Learned about early detection for breast and cervical cancers
    - Brainstormed reasons why some women don't get regular

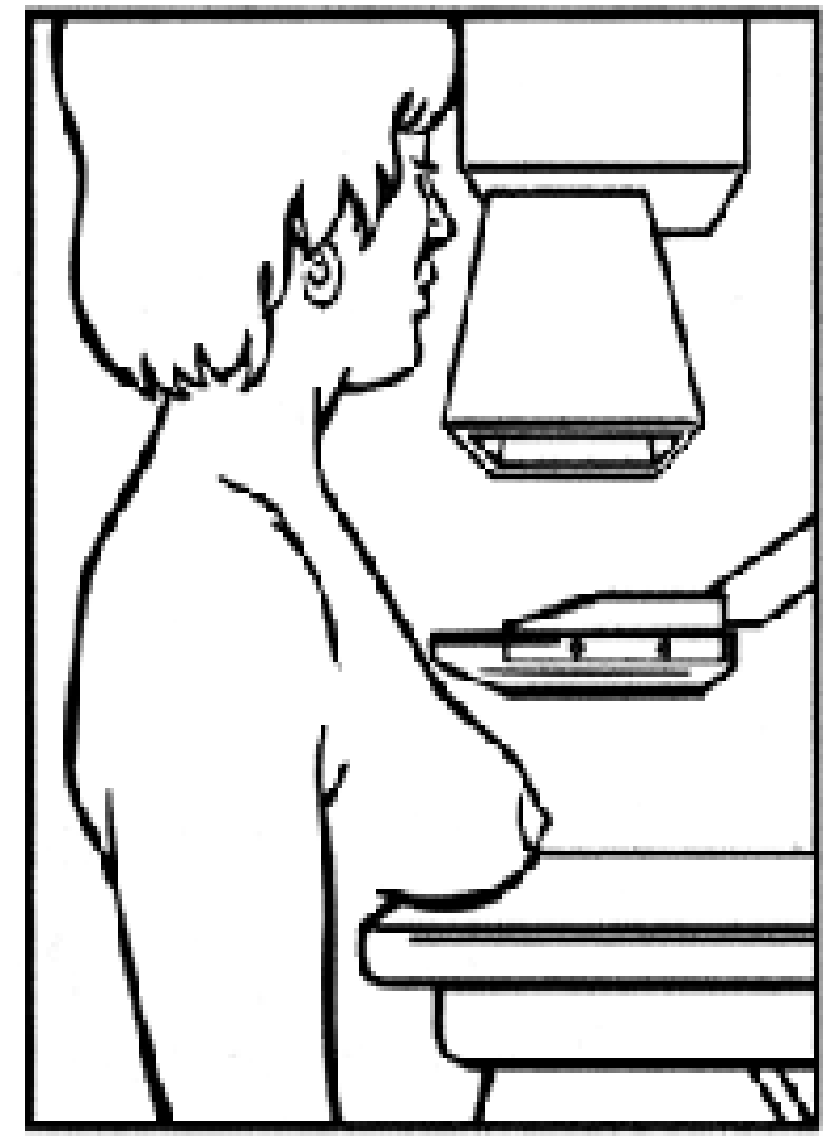
	mammograms and Pap smears - Started to discuss ways to help women overcome barriers to early detection 3. Pass out the "Finding Breast & Cervical Cancer Early" handout #2E. ♦ Like we did in the last session, we have a handout that summarizes the main messages from today's session. You can use this summary of Early Detection Basics to help you remember the information that was presented today. 4. Ask participants for Pluses and Wishes for today's session. ♦ Now we want to talk about what worked and what did not during today's session. Remember, pluses are things that you liked about the session. Wishes are things that you would like to be done differently at future sessions. 5. Ask the group to list some "pluses" first, and then "wishes." *(The trainer should not respond to the wishes, just record them).* ♦ Thank you for all of your input. We appreciate your acknowledgement of the pluses and will try to address the wishes as best we can. 6. Review parking lot. Cross off items that were addressed. Acknowledge those that will be addressed in future sessions. ♦ Were any of the parking lot items addressed? If so, they can be marked off the list. 7. Close session with a prayer led by one of the participants. ♦ To bring our session to a close, _____ is going to lead us in a prayer. 8. Remind participants about the time, place, activities and assignment for the next session. ♦ The next session is: Date: Time: Location:

	♦ At the next session we will be working on our skills for being a good lay health advisor. 9. Thank the group for coming.

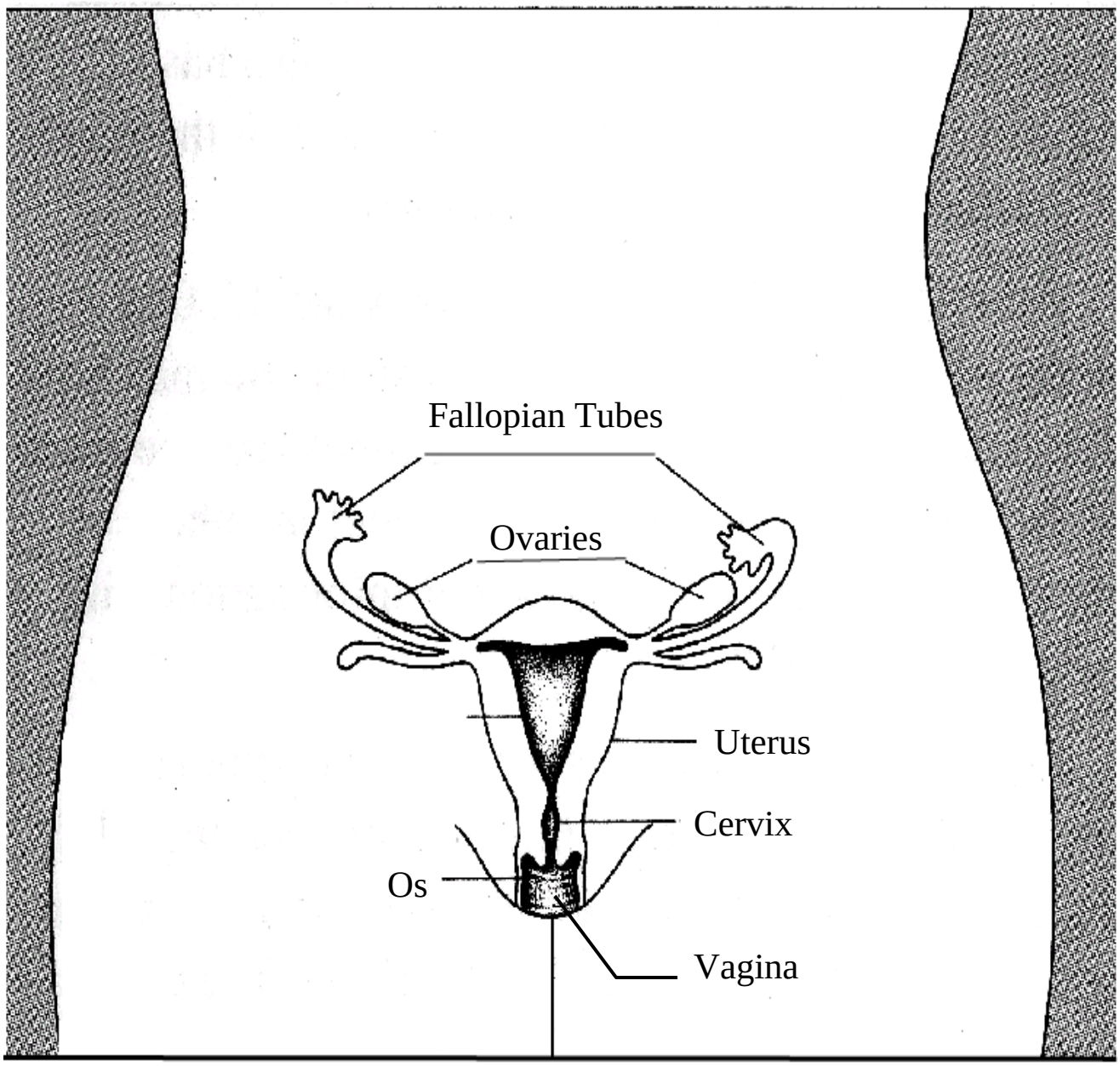
Breast Anatomy

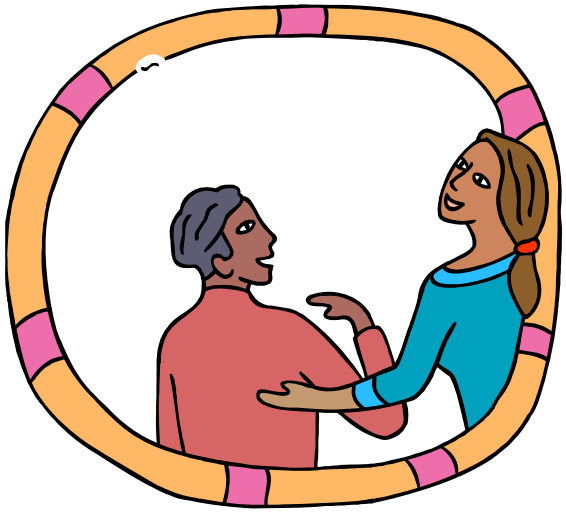


A mammogram is an x-ray of the breast. During a mammogram, you place your breast on a small platform. A paddle is lowered onto the breast from above. The breast is squeezed between the paddle and the platform while an x-ray picture is taken. You should feel pressure during a mammogram. But it should not hurt.



Anatomy of the Female Reproductive System





Supportive Communication

It is important to help women feel comfortable when talking about breast and cervical cancer.

Things we can do to help women feel safe:

- Make eye contact
- Use "open" body language like leaning forward when listening and leaving arms open (not crossed)
- Speak gently and slowly
- Pause and give her time to think about what she wants to say
- Stand or sit close
- Touch her arm, knee or shoulder

Things we can say to help women know that we care:

- Encourage talk with simple phrases like "yes," "OK," "I see"
- Summarize important points
- Tell her that you respect her feelings
- Use "I" language to let her know you understand what she is feeling
    - "I sense you are unsure."
    - "It sounds like you're feeling frustrated."

Finding Breast and Cervical Cancer Early

- Breast and cervical cancers are easiest to treat when they are found early.
- Mammograms and Pap smears are the best ways to detect breast and cervical cancers early.
- Every woman should talk with her doctor about when and how often to have a mammogram and a Pap smear.
- In the case of an abnormal mammogram or Pap smear, a woman should always talk to her doctor about the next step. She should follow through on her doctor's advice right away.

Mammograms

- The best way to find breast changes or a lump that may be cancerous.
- The only way to detect breast changes that are too small to feel.
- Recommended for women 40 years and older.
- Women 50 years and older should have one every year.
- Women 40-49 years and women with a family history of breast cancer should ask their doctor when and how often to have mammograms.

Pap smears

- The best way to find changes on a woman's cervix that may be cancerous.
- Detect abnormal cells before they become cancer cells.
- Recommended for all women beginning with the onset of sexual activity or at 18 years of age – whichever comes first.
- Usually recommended once a year. After 3 normal Pap smears in a row, many doctors recommend having a Pap once every 3 years.

Breast & Cervical Health
Session 2 Role Plays

- **No way Nora**
- **Embarrassed Ethel**
- **Why-Should-I Wendy**

No way Nora

LHA: Hi Nora, how you doin'?

Nora: What are you doing out here?

LHA: I'm talking about mammograms.

Nora: I don't want to hear anything about that. Isn't that about cancer? Now, why would I want to know if I have cancer? That's like telling me I'm going to die. I'd rather not know. I'm not interested, no way.

LHA: Well, Nora, I can see why you might not want to find out you have cancer, but the great thing about mammography is that it can find breast cancer early, while it can still be treated. So, even if you had cancer, it would be better to know so that you could get treatment. Mammograms actually save women's lives! Maybe, you could at least think about getting a mammogram?

Nora: Mmm, I'll think about it, but I don't think that's for me.

LHA: Just think about it. We'll talk again soon.

Embarrassed Ethel

LHA: Hey Ethel, it's so good to see you! Now, you know I volunteer with Save Our Sisters, so I want to ask you something. Have you gotten your Pap smear?

Ethel: Oh, no I haven't. Listen, I know I need to get one, but I just can't. I mean, it so embarrassing. I don't want some other man touching my private parts…it feels disgraceful to me.

LHA: Well, let's think about what might make it less embarrassing. You know, even if a man is performing the procedure, a woman, probably a nurse, will always be in the room. Or, I'd be happy to go with you if it would make you feel more comfortable. But, remember that doctors and nurses are professionals. They perform this test on women all the time because they want women to be healthy. Your health is more important than feeling embarrassed for a few minutes. The Pap smear is the only way to detect cervical cancer early while it can still be treated.

Ethel: I know, you're right.

LHA: Can I help you make that appointment now?

Ethel: Yes. Let's go.

Why-Should-I Wendy

LHA: Hi, Wendy! I'm glad to see you out-and-about again. How are you doing?

Wendy: I'm better. Thanks for bringing that dinner by for Frank and the kids when I was sick. What are you up to these days?

LHA: Well, we're out here at the post office today reminding women about the importance of mammograms. Have you had a mammogram, Wendy?

Wendy: No, and I'm not sure I need to. I see several different doctors for all the problems I have and none of them has ever suggested that I might need one. They probably realize I already spend half my life at the clinic anyway! I sure don't need to make more appointments than I already need.

LHA: Yes, I can understand why you might not want to have to go to the doctor's office for another visit, but taking a mammogram can find breast cancer when it can still be treated. And we're both at an age when it's important to get screened every year. Maybe I could help you look into scheduling a mammogram on the same day as one of your other appointments at the clinic.

Breast & Cervical Health
Session 3

Agenda

- **Arrival/Gathering** (20 minutes)
- **Review/Preview** (10 min)
- **Ice Breaker: Stop, Yield, Go** (20 min)
- **Teaching the Stages of Change & Guess Who?** (30 min)
- **How to Identify a Woman's Mammography & Pap Smear Stages** (20 min)
- **Advising by Stage** (20 min)
- **Role Plays** (35 min)
- **Closing/Evaluation** (20 min)

Learning Objectives

- **Learn about effective techniques for helping women overcome barriers to mammography & Pap screening**
- **Learn skills for advising women about mammography & Pap Smears**
- **Practice new skills for advising women to get screened for breast and cervical cancers**

Total Time

2 hours, 55 minutes plus 10-minute break

Handouts

- **Picture of Susie, Yasmin & Greta (Handout #3A)**
- **STEPS picture (Handout #3B)**
- **Staging handout (Handout #3C)**
- **Lay Health Advising: A Review handout (Handout #3D)**
- **Homework assignment (provider information -- #3E)**

Flipchart templates

- **Session 3 learning objectives**
- **Session 3 agenda**
- **Large pictures of Susie, Yasmin and Greta for sticky wall**

Trainer's Notes	

Arrival/Gathering

Trainers:

Time: 20 minutes

Background: The workshop incorporates 20 minutes for arrival, sign-in, and gathering. At the end of the 20 minutes, participants should be gathered at the table and ready to begin the workshop.

Training Objectives:

At the end of this activity trainers will have:
1. Completed logistical aspects of the workshop.

Materials:

- Name tags
- Pens
- Sign-in sheet
- Refreshments

Steps:

1. Make sure the room is set up before participants begin arriving.
2. Have person(s) greet participants as they arrive.
3. Have table with registration materials clearly displayed. Have all participants sign in and put on name tags when they arrive.
4. Encourage participants to eat and mingle.
5. Inform participants 5 minutes before the start of the session activities so they can begin gathering at the table.

Trainer's Notes	

Review/Preview

Trainers:

Time: 10 minutes

Training Objectives:

At the end of this activity trainers will have:

1. Started the workshop with a safe and comfortable atmosphere.
2. Reviewed the ground rules and added to them if necessary.
3. Reviewed and addressed wishes from Session 2.
4. Summarized what was covered in Session 2.
5. Addressed any questions or concerns regarding Session 2 material.
6. Introduced agenda and learning objectives for Session 3.

Materials:

- Ground rules
- Parking lot
- Pluses and wishes from Session 2
- Session 2 learning objectives
- Session 3 agenda
- Session 3 learning objectives

Steps:

1. After everyone is seated welcome them to the session. Acknowledge any new observers, guest trainers, etc.

2. Open the session with a prayer led by one of the participants.

   - ♦ As we did last time, I'd like to open this session with a prayer. Today _____ is going to lead us in the opening prayer.

3. Remind participants of the ground rules that were created in the first session. (The list should be posted in the room where everyone can see them). Have a participant read the list aloud to the group. Ask the group if they have any questions, changes, or additions to make to the list.

4. Post Pluses and Wishes from previous session. Acknowledge the pluses and explain which Wishes were addressed and how.

	♦ I appreciate the feedback you gave about the last session. These are some of the things that people liked about that session...(list a few pluses). ♦ Some of the suggestions that were made for improving the session were...(list wishes). We could meet these requests (list) by doing (...). However, these requests were beyond the scope of the workshop. ♦ Thank you again for the feedback. We tried to address as many of your suggestions as possible to meet your needs. 5. Review learning objectives from Session 2. Ask if anyone has any questions or concerns from the previous session. ♦ Let us take a look back at what we did last session. Last session we...(read learning objectives). Does anyone have any questions about information or activities from last time? 6. Review the Session 3 agenda and learning objectives. Post on wall. ♦ Now let's look at what we're going to do today. 7. Acknowledge parking lot. ♦ As promised, the parking lot is back to keep track of concerns that come up which we cannot address immediately. We will mark off items as they are discussed. 8. Lead into next activity. ♦ Now let's start with an activity to get us geared up for what we're going to be learning about today - how to effectively advise women to get mammograms and Pap smears.

Trainer's Notes	

Ice Breaker:
Stop, Yield, Go

Trainers:

Time: 20 minutes

Background: This icebreaker introduces concepts of the Transtheoretical Model (TTM) , also known as the Stages of Change Model, which proposes that decision-making is a process of several stages. This activity presents a variety of activities and then shows how people can be categorized based on their "stage" in the decision-making process for each one.

Training Objectives:

At the end of this activity trainers will have:
1. Introduced LHAs to the concept of stages of change and decisional balance.

Materials:

- 'NO WAY' Stop Signs, 'MAYBE' Yield Signs, 'YES' Green Light Signs

Steps:

1. Make sure that each participant has a STOP, YIELD, and GO SIGN.

2. Explain the activity. Participants will explore how people can be grouped according to their attitudes regarding specified behaviors. They will go on to discuss how their feelings or attitudes about specific behaviors influence their decision-making and openness to change.

    - Right now we are going to think about different activities and how we feel about doing them.

3. Explain how the signs will be used and what they represent.

    - I know many of you are wondering about how the Stop, Yield and Green Light signs will be used. As you know, when driving, the stop sign tells us to stop, a yield sign tells us to slow down, and a green light tells us to go. I'm going to ask you about different activities. There are no right or wrong answers. These are just your opinions. I want you to hold up the sign that best fits how you feel about doing the activity. If it is one you would never consider doing, no way, no how, hold up the 'NO WAY' stop sign. If the activity is one you could

possibly see yourself doing, hold up the 'MAYBE' yield sign. If you wouldn't hesitate to do the activity, hold up the 'YES' green light sign.

4. Clarify any questions the participants may have regarding use of the signs.

5. Ask the prepared questions, providing ample time for the respondents to think about and display their responses.

   Who would:
   - Roll through a stop sign?
   - Walk/campout in the middle of the night at the Relay for Life?
   - Wear her hair in an afro?
   - Eat raw fish or sushi?
   - Stay up all night playing pinochle?
   - Take a yoga class?
   - Be willing to go on national television to talk about breast cancer?

6. Facilitate discussion about participants' choice of signs.
   Note to trainer: Take note of questions that resulted in the most varied responses. Orient the following discussion around question(s) for which there was the greatest variation.

   ♦ Let's go back to the question about...I noticed that there were a lot of different answers to this question. I think it will be helpful to talk about why each of you chose the sign you did. Who held up a green sign? Can you tell the rest of us why you would definitely do (insert activity)? What about those of you who picked the YIELD sign? Would any of you like to share why you would maybe (insert activity)? What keeps you from saying 'yes' right now? Who held up the STOP sign? Will some of you share with the group why you feel the way you do about (insert activity)? We see that holding up one sign or the other is based on how we feel about the activity. We have more negative feelings about things that we would not do. We have more positive feelings about things that we would do.

7. Lead into next activity

   ♦ I bet most of you are wondering what using stop signs, yield signs and green lights to describe how you feel about different activities has to do with being a lay health advisor. The next activity will begin to show you how these signs relate to advising women about mammography and Pap smear screening.

Trainer's Notes	

Teaching the Stages of Change & Guess Who?

Trainers:

Time: 30 minutes

Background: This session presents an overview of the "stages of change" and how they relate to breast and cervical cancer screening.
The presentation uses three characters: Susie STOP, Yasmin YIELD and Greta GO. The characters make the stages less abstract by providing a familiar context. Most of the women will be able to identify women who are similar to those presented in the training.

Traditional approaches to teaching TTM use both past behavior and future intention for staging. This training, however, uses future intention only. We excluded past behavior to simplify the model. Therefore, LHAs will not learn about relapse, or that some precontemplators may have once been active. In this training, a precontemplator (Susie STOP) is defined as a woman who is not now thinking about getting a mammogram regardless of her past behavior. A contemplator (Yasmin YIELD) is defined as a woman who is thinking about getting a mammogram but has no plans to get one in the near future.

As a simplification, this program teaches that knowledge barriers are the primary reason Susie STOP does not think about getting a mammogram. Yasmin YIELD has the necessary knowledge but has to overcome access barriers.

The introduction of the three characters is followed by a game in which participants are asked to apply the concepts of these characters to Pap smear screening. The activity should help participants to think critically about the characteristics of women at each stage.

Training Objectives:

At the end of this activity trainers will have:

1. Introduced Susie STOP, Yasmin YIELD and Greta GO.
2. Described how the "stages of change" apply to mammography and Pap smear screening.
3. Provided participants with an interactive environment in which they can apply "stages of change" concepts.
4. Helped participants understand how the stages of change apply to both Pap smear and mammography screening.

Materials:

- Pictures of Susie STOP, Yasmin YIELD and Greta GO to hand out to participants (Handout #3A)
- Pens and pencils
- Flipchart
- Big Susie STOP, Yasmin YIELD, and Greta GO pictures to put on sticky wall
- Sentence strips with descriptions of Susie STOP, Yasmin YIELD, and Greta GO

Steps:

1. Place Susie STOP, Yasmin YIELD, and Greta GO foam core cut-outs on the sticky wall. Leave space beneath each picture for the steps that will come later.

2. Distribute pictures of Susie STOP, Yasmin YIELD and Greta GO and describe what each represents.

   - Now I am going to introduce three ladies to you: Susie STOP, Yasmin YIELD and Greta GO. As I begin telling you a little bit about each of them, you will probably realize that you know women just like these three. I think it will help you to remember how these women are similar and different from one another by writing down on each woman's picture what I share with you about her. There are pens and pencils on the tables.

   - I am going to talk to you about Susie STOP, Yasmin YIELD and Greta GO's mammography practices. As we get further along in our discussion about them, you'll see that Susie STOP, Yasmin YIELD, and Greta GO's attitudes apply to any behavior you can think of.

3. Introduce Susie STOP.

   - Susie STOP is the woman holding the red STOP sign. Can any of you guess what Susie thinks about mammograms? (Let participants answer)

     Examples of correct answers are:
     - she doesn't want to get one.
     - she doesn't want to know if she has cancer.

   - Many of your ideas are right on. Susie doesn't really think about

	having a mammogram, which is why she is holding the STOP sign. It helps you remember that women who don't think about having mammograms are at STOP for the behavior. If you know someone like Susie, what reasons does she give for not getting a mammogram? *(List ideas*.) ♦ Those are great ideas. (*Note to facilitator: You may want to add from the list below*.) Some other reasons to think about are: - not knowing what a mammogram tests for - not knowing why mammograms are important - believing that a mammogram is only necessary for women with symptoms - being worried that a mammogram can cause cancer - believing that cancer is always fatal - not hearing from her doctor that she should get one (particularly a problem for women who see specialists instead of general practitioners) ♦ Basically, Susie is at STOP because she doesn't know why she should get a mammogram. 4. Introduce Yasmin YIELD. ♦ Now let's talk about Yasmin YIELD. She is the woman holding a yellow YIELD sign. What do you believe Yasmin thinks about mammograms? (Let participants answer and list their ideas.) Example of a correct answer is that she's maybe going to get a mammogram. ♦ Yasmin is considering going for a mammogram. That's why she is wearing the YIELD sign. It helps you remember that women who are thinking about getting a mammogram but haven't gotten one yet are not at STOP but they aren't at GO either. You can also think about it this way-remember the last activity we did? There, the YIELD sign read 'MAYBE'. That's a perfect description for how Yasmin feels about mammograms. She's maybe going to get one, but she's not entirely sure she will. ♦ Unlike Susie, Yasmin may know that mammograms are important. Certain things keep her from going for a mammogram. If you know a woman like Yasmin, what reasons does she give for not getting a mammogram? *(Note to facilitator: You may want to add from the list below.)*

Some other reasons could be:
- embarrassment about the procedure (including such issues needing help to stand at the mammography machine, dress or undress, etc.)
- worry about it being painful
- cost/not enough money
- doesn't have time
- worried about what she might find
- too much hassle to deal with right now
- not knowing where to go
- not knowing about mammography facilities that are specially equipped for women with disabilities

♦ Yasmin is at YIELD because of barriers. She knows the good things about mammography- it's the barriers or bad things that keep her from going.

5. Introduce Greta GO.

♦ Greta GO is on the last picture you have. She's got the GREEN GO sign. What does Greta think about mammograms? (Let participants answer.)

Examples of correct answers are: she gets mammograms, she doesn't just think about getting mammograms, and she knows why mammograms are good.

♦ Greta is different than Yasmin because she doesn't just think about going for a mammogram--she gets mammograms! The Green light on her shirt tells you that she is going for mammograms. Why is Greta going for mammograms? (Let participants answer. Steer participants towards: she knows the good things about mammograms and has overcome all the barriers that keep her from getting one.)

♦ Those all are great reasons. If you know women like Greta or you are like Greta and always go for your mammogram, will you share why with the rest of the group?

♦ We can summarize what you all have said like this: Women like Greta GO for mammograms because they know why they are important and are able to overcome all the hard things that keep them from getting them. We want to get all our sisters to be like Greta and GO for mammograms. We'll talk more about how to do this later.

6. Link with Pap smear screening and lead into "Guess Who" game.

- Even though we learned about Susie STOP, Yasmin YIELD, and Greta GO for mammography, it's important to remember that the descriptions of these women can also be applied to Pap smear screening or any behavior for that matter. Our next activity is going to help you think about characteristics of Susie STOP, Yasmin YIELD and Greta GO for Pap smear screening.

7. Explain the activity.

   - Now, we are going to play a game called 'GUESS WHO?' I am going to pass each of you a sentence strip. Each sentence strip describes how a woman might feel about getting a mammogram or Pap smear. On the sticky wall, there are three columns: a STOP sign for Susie STOP, a YIELD sign for Yasmin Yield and a GREEN light for Greta GO.

   - I'm going to ask each of you to read your sentence strip aloud and then place it under one of the three columns on the sticky wall. I'd like you to share with the rest of the group why you put your strip under the category you chose. That way we can all learn together.

8. Distribute sentence strips. *(Trainer can use as many strips as needed depending on the size of the group.)*

   Susie Stop:
   -Is not thinking about having a Pap smear
   -Thinks that Pap smears are only important for women with symptoms
   -Thinks that only women who are sexually active need to have a Pap smear
   -Doesn't think about going for a Pap smear since her doctor didn't recommend it
   -Doesn't think either Pap smears or pelvic exams are important for women past their childbearing years
   -She doesn't want to know if anything is wrong with her

   Yasmin Yield:
   -Would consider having a Pap smear but is not ready yet
   -Knows why Pap smears are important but is worried about the cost of getting one
   -Knows that Pap smears can find cancer early but is embarrassed about having the doctor touch her down there
   -Knows that all women 18 and older should have Pap smears regularly but her last one was very painful
   -Would consider getting a Pap smear if she could find a female doctor

Greta Go:
-Is going for Pap smears regularly
-Has overcome all of the hard things that would keep her from getting a Pap smear
-Has asked her daughter to drive her to the doctor's office since she knows that getting a regular Pap smear can detect cervical cancer early
-Goes for a Pap smear even though she is worried that her husband might not think she's modest

Combinations (Participants should have to think about these and not know where to put sentence strip):
-Gets a mammogram every year but doesn't think about getting a Pap smear since her partial hysterectomy—*answer: Greta Go for mammography, Susie Stop for Pap smear screening*
-Is thinking about getting both a mammogram and Pap smear—*answer: Yasmin Yield for both behaviors*
-Always gets a Pap smear during her yearly well-check up with her doctor but doesn't get a mammogram—*answer: Greta Go for Pap smear screening; Susie Stop for mammography*
-Thinks that bruising when getting a mammogram can cause cancer and that a Pap smear is only for women who have multiple sexual partners—*answer: Susie Stop for both behaviors*
-Always goes for both a mammogram and Pap smear***—answer: Greta Go for both behaviors***

9. Have each participant read her sentence strip aloud to the group as she places it under the appropriate sign on the Sticky Wall. Each woman should explain her decision.

10. Discuss strips that are confusing or incorrectly assigned during the activity as LHAs post them.

11. Lead into next activity.

- Now that we know more about what it means to be Susie STOP, Yasmin YIELD, and Greta GO, we want to talk more about what all this means to you as an LHA.

Remove sentence strips, but leave foam core cut-outs of Susie, Yasmin and Greta on wall for next activity.

Trainer's Notes	

How to Identify a Woman's Mammography and Pap Smear Stage

Trainers:

Time: 20 minutes

Background: This segment of the training helps LHAs apply stages of change, or STEPS, to their advising activities. LHAs will brainstorm strategies for identifying a woman's stage of change or "step".

Note to Facilitator: *Before delivering this segment of the training, please familiarize yourself with the handout on staging. It is necessary to integrate these concepts into the discussion about what questions are most appropriate for identifying a woman's stage of change.*

Training Objectives:

At the end of this activity trainers will have:

1. Linked Susie STOP, Yasmin YIELD and Greta GO to stages of change.
2. Facilitated discussion about how to stage women before advising about mammography and Pap smear screening.

Materials:

- Flipchart
- Markers
- Strips to make steps on the wall
- Large pictures of Susie Stop, Yasmin Yield, and Greta
- Handout of Steps picture for participants (#3B)
- Handout on staging (#3C)

Steps:

1. Synthesize information from last two activities.

    - Let's quickly review what we just did. We met three ladies, Susie STOP, Yasmin YIELD, and Greta GO and considered how they behave for mammography and Pap smear screening. We talked a little bit about how a woman may be a Susie STOP for mammography and Yasmin YIELD for Pap smear screening. Now, we are going to spend some time thinking about how their beliefs relate to your lay health advising.

2. Stagger the placement of Susie, Yasmin, and Greta on the sticky wall ascending left to right with Susie lower left, Yasmin mid-space and Greta higher right. Place black construction paper strips under the cut-outs to represent stairs.

3. Discuss the relationship between Susie STOP, Yasmin YIELD and Greta GO.

   - ♦ See the STEPS I've built between Susie STOP, Yasmin YIELD, and Greta GO? I'm going to pass out copies of a picture that looks like our sticky wall.

   - ♦ Let's talk about Susie STOP, Yasmin YIELD and Greta GO's mammography behaviors again. Who can tell me about Susie? (*Solicit answers from participants and summarize.*) Susie does not think about getting a mammogram. She's at STOP for this behavior.

   - ♦ Who wants to tell me about Greta and mammography? (*Solicit answers from participants and summarize*.) Exactly, Greta is getting mammograms regularly. She's at GO for mammography.

   - ♦ What about Yasmin? Yes, she is thinking about getting a mammogram. She's not at STOP like Susie because she's thinking about getting one but she's not at GO like Greta either.

   - ♦ So now we've got Susie on the bottom step, Yasmin in the middle and Greta on the top step. What do you think I'm trying to show you? (Sample responses include: getting a mammogram happens in steps; change happens over time; people don't change all at once.)

   - ♦ Those are great ideas. I want you to see is that these women are at different steps for mammography: STOP, YIELD, and GO.

4. Review link between characteristics of individual stages and the STEPS.

   - ♦ Let's talk a bit about what it means to be at STOP for mammography. Why doesn't Susie think about getting a mammogram? (Solicit answers from group and write on a blank sheet of white paper under STEPS between the STOP and YIELD signs.)

	♦ As you can see, I have written your answers between this STEP and the next one. Not knowing the importance of mammograms and early detection is what keeps women from moving from STOP to YIELD. ♦ Now think about what if means to be at YIELD for mammography. Why is Yasmin only thinking about getting a mammogram? (Solicit answers from group and write on blank piece of white paper under STEPS between YIELD and GO SIGNS.) ♦ These barriers keep women who are thinking about getting a mammogram from making plans to get one. They are the difference between YIELD and GO. ♦ Women at GO get mammograms. What are some reasons why? (Solicit answers from group) 5. Explain the process of STEPS. ♦ We've just described the different stages women can be in for mammography. These stages also apply to Pap screening. The decision to do something new or to repeat a behavior, like going for a Pap smear, happens over time, in stages or STEPS. Knowing that there are STEPS to going for a Pap smear helps you understand why it takes a long time to convince some women to go. And why with other women, it takes only a few words of encouragement or giving them a ride to the doctor's office. 6. Brainstorm ideas for identifying woman across STEPS. ♦ Now, let's think about how to figure out whether a woman is at the STOP, YIELD, or GO STEP for mammography and Pap smear screening. What are some of the things you would say to a woman to find out what STEP she is on? *Note to Facilitator: As participants share, write ideas down on flip chart. After a few minutes of idea gathering, discuss what group has shared, whether participants believe they would say certain things and under what circumstances. Trainer will have to make sure that the participants include a focus on future intention in their questions. For example, are you thinking about having a mammogram in the next year? (Post pages in room for rest of training)* ♦ [Pass out staging handout.] Here are some helpful hints for

	identifying a woman's STEP. To find out if a women is at STOP for mammograms or Pap smears, ask her if she **knows.** The key word to listen for with a Susie STOP is **no**. To find out if a woman is at YIELD for either behavior, ask her if she **does**. The key words to listen for with her will be **if**, **but**, or **maybe**. A woman who is at GO will answer **yes** to both questions. 7. Clarify that participants must figure out an advisee's STEP for both mammography and Pap smear screening. ♦ Even though you will be talking to women about both mammography and Pap smear screening, you will need to figure out what STEP a woman is in for mammography and what STEP she is in for Pap smear screening separately. This is because a woman may be at STOP for Pap smear screening but at GO for mammography. To try figure out what STEP she is in for both behaviors at the same time is too confusing. Pick mammography or Pap smear screening, figure out what STEP she is in, and advise her about that. Then move on to the other behavior. 8. Wrap-up and lead into next activity. ♦ Now we are going to take a quick break. When we come back, we will talk about how to get our sisters closer to GO for both mammography and Pap smear screening.

B R E A K

Trainer's Notes	

Advising by Stage

Trainers:

Time: 20 minutes

Background: This activity teaches the concept of decisional balance and how it relates to LHA advising. Decisional balance is the weight an individual assigns to the pros and cons of engaging in a specified behavior such as mammography or Pap smear screening. Participants will learn to:

- WITNESS about BENEFITS for women at STOP,
- LIGHT THE WAY about BARRIERS for women at YIELD, and
- PRAISE women they identify at GO.

The spiritual orientation of LHA messages is grounded in focus group findings, which identified spirituality as a shared value of LHAs and the target population.

Because this is a detailed mini-lecture covering complex information, the trainer needs to be well-versed in the concepts of decisional balance.

Training Objectives:

At the end of this activity, trainers will have:

1. Introduced the concept of decisional balance and how it relates to stages of change.
2. Explained how to tailor messages to shift an individual's decisional balance in favor of mammography.

Materials:

- Scale (two-sided balance)
- Pros and cons "block"
- Lay Health Advising: A Review handout (#3D)

Steps:

1. Explain the concept of decisional balance.

    - Now we are going to begin to discuss how to get our sisters to GO! The first thing we need to understand is how people make decisions. Think about decision making as a double sided scale. (*Show the scale and point to each side labeled pros and cons as you talk.*) This scale measures the weight of the pros and cons for getting a mammogram or Pap smear. Pros are the good

	things people believe about a behavior. Cons are the bad things people believe about a behavior. People's decisions reflect which they think weighs more-- the pros or the cons. 2. Link decisional balance with stages of change. ♦ Decisional balance is an important part of the STEPS we talked about earlier. ♦ Let's think about women at STOP. (*Load the cons side of the scale with 2-3 blocks and leave the pro side empty*.) So far, we know that they are not thinking about getting mammograms and some of the reasons why, including not knowing about the importance of mammograms or who is at risk for breast cancer. Women at STOP don't know any of the good reasons or pros for getting mammograms. For women at STOP, the CONS weigh much more than the PROS because there aren't any PROS to balance out the CONS. As you may have already guessed, this has a lot to do with why she is at STOP for mammography. Since she doesn't know any of the good reasons for getting mammograms, we can't possibly expect her to think about getting one. ♦ Now we'll talk about women at YIELD. A woman at YIELD has thought about the pros for mammography. (*Load the pros side with equal blocks to balance the scale*.) These women believe there are good things about getting mammograms, such as finding cancer early, peace of mind, and taking care of her health so she can take care of others. But they also believe that there are bad things or hassles involved, like inconvenience, pain, money, or worry about finding a problem. This is why women at YIELD are thinking about getting a mammogram but are not committed to getting one yet. ♦ Women who are at GO believe the pros or good things about getting mammograms weigh more than the CONS. (*Remove one block from the cons so the scale tips in favor of the pros. Do <u>not</u> remove all the blocks from the cons side*.) That's why women at GO are going for mammograms. Women at GO know the benefits outweigh any possible disadvantages. 3. Explain how shifting decisional balance or reevaluating the pros and cons creates movement across the stages. ♦ I'm sure many of you are wondering what all this information

about the pros and cons means. At each STEP, you as LHAs can use what you know about which weighs more, the pros or the cons, to advise women about mammograms and Pap smears. To move women closer to GO, you must give women information that helps tip the scale in favor of the pros.

4. Introduce WITNESS (or TESTIFY) about benefits, LIGHT the WAY about barriers, and PRAISE

   - Now we are going to talk about how we can increase the weight of the pros at each "step". (*The facilitator may choose to continue using the scale if it is helpful to illustrate the concepts.)*

   - We'll start with women who are at STOP. For women who are at STOP, the CONS are heavier than the PROS. How can we increase the weight of the pros? We need to tell her all about the good reasons to get a mammogram. When you meet a woman at STOP, you will WITNESS to her about the pros of mammography. When I say WITNESS about the pros of mammography, I mean tell a woman about your experience with mammograms, and personal stories about how it changed your life. You can share personal stories you've heard about how mammograms can save lives. Can anyone share some examples of WITNESSING about the benefits of mammography with the group?

     (For facilitator, an example of WITNESSING:"I get mammograms because they keep me healthy for my husband and children. I've got a lot to live for and so do you.")

   - Women at YIELD give equal weight to the pros and cons of mammography. They know the benefits already, but as an LHA you can help decrease the cons. When you meet a woman who is at YIELD, you can LIGHT THE WAY about overcoming barriers. LIGHTING THE WAY means identifying what a woman believes is keeping her from getting a mammogram and helping her find ways to overcome those obstacles. One example would be telling a woman who worries that mammograms are too expensive about the Breast and Cervical Cancer Control Program (BCCCP), which helps women who can't afford to get a mammogram get one. (An example of LIGHTING THE WAY: "I know its hard for you to get to a mammography center, but if you tell me when you need to be there I'll be happy to take you.")

	♦ Women at GO know the pros outweigh the cons. You don't need to change this! Instead, you should PRAISE them about how they are getting mammograms because it's easy to backslide! A woman may delay because she's busy and before she knows it one or two years have passed and she hasn't been back for a mammogram. Encourage women who are at GO to stay on schedule. Does anyone have an example of what PRAISING would sound like? *Pass out Lay Health Advising: A Review handout* 5. Link to next activity ♦ In the next activity, we will practice using all of these concepts about advising we've been talking about.

Trainer's Notes	

Role Plays

Trainers:

Time: 35 minutes

Background: The purpose of this activity is to provide participants an opportunity to apply the information learned throughout the training session. Scenarios will be structured so that participants will identify an individual's stage of change and deliver a corresponding stage-appropriate message.

Training Objectives:

At the end of this activity trainers will have:

1. Helped participants apply the concepts learned throughout the training session.
2..Facilitated discussion about how participants integrated the concepts of stages of change and decisional balance into stage-appropriate advising.

Materials:

- Role plays

Steps:

1. Introduce the idea of using a conversation starter to begin talking to women about these topics.

    - Before we practice using our new skills, one thing to think about is how to begin a conversation with a woman about mammograms or Pap smears. It might make the conversation flow more smoothly if you can tie in information from the local news about health or parts of a sermon you just heard about taking care of yourself or your family. Can anyone think of some conversation starters they might use?

2. Have volunteers act out role of LHAs in scenarios. Facilitator will play part of "advisee". Use the following discussion questions after each scenario is acted out?

    - What STEP was _____? Did _____correctly identify her STEP?

- How did _____ identify her STEP? What do you think about this approach? Did it work?
- Which weighs more at this STEP? The pros or the cons?
- What _____ say to try and change the weight between the pros and cons?
- Did this advice match with her STEP?

Character Scenarios

Character Scenario 1: No way Nora

LHA: (Use conversation starter to introduce self to "advisee", try to figure out STEP for Pap smear screening)

Nora: I'm not interested in hearing anything about Pap smears. Isn't that the test that they do to tell you if I have cancer or not? Now, why would I want to know if I have cancer? That's like telling me I'm going to die If I'm going to die, I'd rather not know before hand.

LHA: (Advise based on what Nora told you)

Note to facilitator: LHA should be Witnessing about the Pros of Pap smear screening to Nora. She is obviously at STOP for Pap smear screening. LHA could remind Nora that the earlier cancer is found, the easier it is to treat. Finding cancer early through a Pap smear greatly increases your chances of beating it. LHA could also point out that finding cancer early through a Pap smear is important to do for your family since they care about you and need you to be healthy.

Character Scenario 2: Embarrassed Emily

LHA: (Use conversation starter to introduce self to "advisee", try to figure out STEP for Pap smear screening)

Emily: I know I need to get one, but I just can't. I mean it is so embarrassing to lay there with the doctor looking at you and touching you down there. It's so disgraceful!

LHA: (Advise based on what Emily told you)

Note to facilitator: LHA should recognize that Emily is at YIELD for a Pap smear and LIGHT THE WAY by helping her overcome barriers. LHA

	could tell her that modesty is important but not so much that you should risk your health. LHA could stress that all women should have this normal medical procedure that allows the doctor to examine their internal organs. LHA could also recommend a female provider and tell her that she could request that a female nurse be present, which could make it more comfortable. **Character Scenario 3: Combination Connie** LHA: Introduce yourself to "advisee" and try to figure out STEP for mammography and then Pap smear screening) Connie: A mammo-what? I don't know what you are talking about. LHA: Advise based on what Connie told you and then transition to Pap smear screening. *Note to facilitator: Connie is at STOP for mammography. LHA should WITNESS about PROS. LHA should explain exactly what is involved in getting a mammogram, where Connie can go to get one (including referrals if necessary) and why they are important. LHA then can ask about Pap smear history.* Connie: Of course I get a Pap smear. What woman wouldn't? The doctor automatically does it when he checks me down there. LHA: Advise based on what Connie told you. *Note to facilitator: LHA should PRAISE Connie for taking care of her health because she is at GO for Pap smear screening.* **Character Scenario 4: Practicing Penny** LHA: (Introduce yourself to "advisee" and try to figure out her stage) Penny: I just got my Pap smear last week. I was really scared that it would hurt real bad but I realized that not knowing if I had cervical cancer could hurt way worse. LHA: (Advise based on Stage) *Note to facilitator: Penny is at GO for Pap smear screening. LHA should PRAISE Penny for taking care of herself and for overcoming her fears.*

Character Scenario 5: Need-A-Hand Natasha

LHA: (Introduce yourself to "advisee" and try to figure out STEP for mammography and then Pap tests.)

Natasha: I should get one but it's such a hassle! You'd think that the doctor's office, of all places, would have an entryway big enough for my wheelchair. But, I always have a time getting in and out. Plus, I would have to find a friend to go with me. And she needs to be a GOOD friend – someone I wouldn't mind asking to help me get my clothes on and off. And she better be strong too! It's hard work to get me up out of this chair and to keep me propped up in front of that machine.

The one time I had a mammogram, the lady wasn't very nice about calling an aide to help me stand. Then she complained that the films weren't good quality because I wasn't in a good position. I'm not sure she ever got what she needed.

LHA: (Advise based on what Natasha told you and then transition to Pap smear screening.)

Note to facilitator: Natasha is at YIELD for mammogram because she knows she should go but she doesn't want to. LHA should LIGHT the WAY by suggesting questions Natasha can ask when she makes her appointment. For instance, is the building wheelchair accessible? Can someone on staff assist her through the entire exam, including dressing and standing? Does the clinic have a machine that can film a woman who is seated?

Natasha: Yes, I know I should get a Pap smear, but getting onto the exam table – it's a nightmare! Ha! I'd rather have a mammogram and you already heard what I think about those!

Note to facilitator: Natasha is at YIELD for Pap screening. LHA should LIGHT the WAY by encouraging Natasha to call for an appointment because cervical cancer is preventable. Natasha should ask her provider if there is a special exam table or any special procedures in place to help women in wheelchairs have a Pap test. The LHA could offer to help make this phone call.

3. Acknowledge the effort put forth by the participants in the role plays.

    - Great job everyone! You all are well on your way to being excellent lay health advisors. The more you practice these advising skills, the more comfortable you will become with lay

	health advising. 4. Link to closing. ♦ I wish we had more time to practice advising as a group, but we must bring today's session to close now.

Trainer's Notes	

Closing/Evaluation

Trainers:

Time: 20 minutes

Background: The closing part of the training provides an opportunity to reflect on what was covered in the session and gather feedback on how to improve the session. Because of the large amount of information about breast and cervical cancer presented at each session, it is important to review and reinforce the distinctions and similarities between the two cancers. An assignment is also included in the curriculum to help participants apply what they learned in the session and to gather information for the next session.

Training Objectives:

At the end of this activity trainers will have:

1. Summarized the session activities.
2. Reviewed the similarities and differences between breast and cervical cancer.
3. Gathered feedback from the group about the session.
4. Encouraged participants to gather information that will be used in the next session.

Materials:

- Session 3 learning objectives
- Session 3 agenda
- Parking lot
- Markers
- Incentive: Flashlights
- Homework assignment – Handout #3E

Steps:

1. Introduce closing and evaluation.

    ♦ We did a lot today. Let's review what we covered today.

2. Summarize learning objectives.

    ♦ Today we…
    -Learned about effective techniques for helping women

	overcome barriers to getting mammograms and Pap smears -Learned skills for advising women about mammograms and Pap smears -Practiced new skills for advising women to get screened for breast and cervical cancers 3. Review the relationship between breast and cervical cancer. ♦ We didn't talk in as much detail about breast and cervical cancer today, but we did talk about advising women about breast and cervical cancer. Based on what we did today, is there anything we can add to our lists regarding how the two cancers are similar and how they're different? 4. Write participants responses on flipchart pages labeled "similar" and "different". <u>Some sample responses for "similar" might include:</u> -behavior change occurs in steps for both breast and cervical cancer screening <u>Some sample responses for "different" might include:</u> -women may be at different steps for breast and cervical cancer screening -women may need to be advised differently for breast cancer screening than for cervical cancer screening, depending on their step for each behavior 5. Ask participants for Pluses and Wishes for today's session. ♦ Now we want to talk about what worked and what did not during today's session. Remember, pluses are things that you liked about the session. Wishes are things that you would like to be done differently at future sessions. *6.* Ask the group to list some "pluses" first, and then "wishes." *(The trainer should not respond to the wishes, just record them).* ♦ Thank you for all of your input. We appreciate your acknowledgement of the pluses and will try to address the wishes as best we can. 7. Review parking lot. Cross off items that were addressed. Acknowledge those that will be addressed in future sessions. ♦ Were any of the parking lot items addressed? If so, they can be

marked off the list.

8. Explain homework assignment. Pass out "Getting a Mammogram/Pap Smear" handout.

   - Next week one of the things we will be talking about is resources in the community that can help women get screened for breast and cervical cancer.

   - *(Optional)* To get us ready, you all have a brief homework assignment to complete before that session. I would like for half of you to find out some information about where a woman can go in your community to get a mammogram and the other half of you to find out where a woman can go to get a Pap smear. Some of you may already know this information, but we may find out something new from each other when we share our information.

   - We have a worksheet with some things to find out about the place where a woman can get a mammogram or Pap smear. They include:
     -What is the name of the place?
     -What is the phone number?
     -Where is the place?
     -When are they open?
     -How much does it cost to get a mammogram/Pap smear?
     -Is there financial assistance available?
     -Is there transportation to the place?
     -Does a woman have to have a referral to get a mammogram there?

   - Look at the worksheet you have to see whether you will be finding Pap smear or mammography information.

9. Close session with a prayer led by one of the participants.

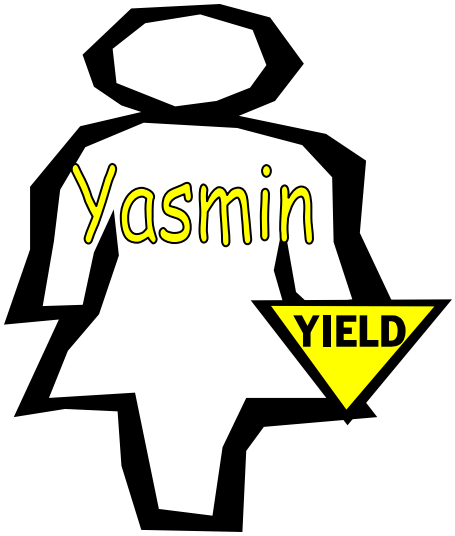
   - To bring our session to a close, _____ is going to lead us in a prayer.

10. Pass out Lay Health Advising: A Review sheet and incentives (flashlights). Link the incentive to the topic of the session.

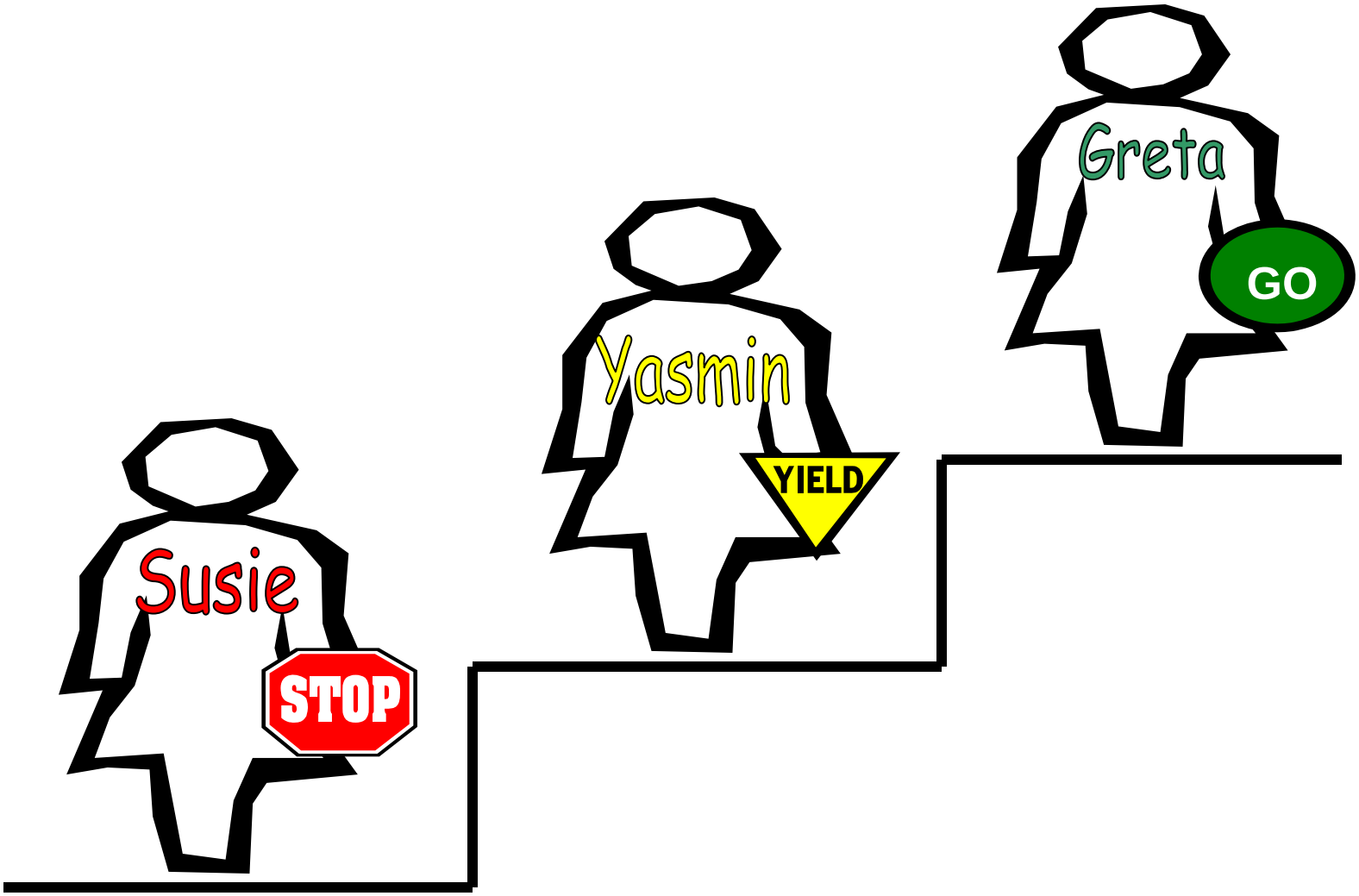
    - To thank you for your participation today, we have flashlights to remind you to LIGHT THE WAY for our family members and friends about mammography and Pap screening.

	11. Remind participants about the time, place, activities and assignment for the next session. ♦ The next session is: Date: Time: Location: ♦ At the next session we will be learning about how the health care system works and what resources are available for women who need breast and cervical cancer screenings. 12. Collect name tags. 13. Thank the group for coming.


Greta
GO


Yasmin
YIELD


Susie
STOP


Susie
STOP
Yasmin
YIELD
Greta
GO

What will she say?

Helpful Hints for Staging Women

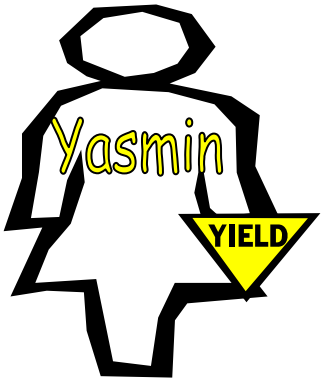
If you are talking with a woman about getting a mammogram or Pap smear, it is important to **ask the right questions** and to **really listen** to what she is telling you about her behavior and the reasons she may or may not be getting them.

To help, here are some **key questions** to ask and **key words** you can listen for to help figure out a woman's stage of change.

Ask if she *knows*…
Do you know about mammograms and Pap smears?

KEY WORDS: **"**No," "Don't Know"

Susie needs <u>information and facts</u>.



Ask if she *goes*…
Do you get mammograms and Pap smears?

KEY WORDS: "If," "But," "Maybe"

Yasmin needs <u>help overcoming barriers</u>.

Ask if she *goes*…
Do you get mammograms and Pap smears?

KEY WORDS: "Yes," "Definitely"

Greta needs <u>praise for her healthy actions.</u>

LAY HEALTH ADVISING: A REVIEW

- **WITNESS ABOUT BENEFITS:**

  Who? Women at STOP

  Why? Since they do not know any of the good things about mammograms or how early detection saves lives, women at this STEP have no PROS to balance out the CONS. This is why they aren't thinking about going for a mammogram.

  How? Share personal experiences with mammography and stories about how mammograms save lives.

- **LIGHT THE WAY:**

  Who? Women at YIELD

  Why? Women at this STEP know the PROS of mammography, but they need help overcoming the CONS that keep them from getting one**.** This is why they are only thinking about going for a mammogram.

  How? Talk to women at YIELD about the things that keep them from going for a mammogram and help women come up with ideas to overcome them.

- **PRAISE**

  Who? Women at GO

  Why? Women at this STEP know the PROS of mammography outweigh the CONS. That's why they are GOING for mammograms.

  How? Tell women at GO that they are doing a great job taking care of their health. Encourage them to continue going for mammograms.

Handout #3E

Getting a Mammogram

Where can you get a mammogram?

_____

What is the phone number and address?

_____

When are they open?

_____

What accommodations do they offer for women with disabilities?

_____

Getting a Pap smear

Where can you get a Pap smear?

_____

What is the phone number and address?

_____

When are they open?

_____

What accommodations do they offer for women with disabilities?

_____

Breast & Cervical Health
Session 3 Role Plays

- **No Way Nora**
- **Embarrassed Emily**
- **Combination Connie**
- **Practicing Penny**
- **Need-a-Hand Natasha**

No Way Nora

LHA: (Introduce yourself to Nora; try to figure out STEP for mammography screening.)

Nora: I'm not interested in hearing anything about mammograms. Isn’t that the test that they do to tell you if I have cancer or not? Now, why would I want to know if I have cancer? That’s like telling me I’m going to die. If I’m going to die, I’d rather not know beforehand.

LHA: (Advise based on what Nora told you.)

Embarrassed Emily

LHA: (Introduce yourself to Emily; try to figure out STEP for mammography screening.)

Emily: I know I need to get one, but I just can’t. I mean it is so embarrassing to put your breast on that machine. Its so disgraceful!

LHA: (Advise based on what Emily told you.)

Combination Connie

LHA: (Introduce yourself to “advisee” and try to figure out STEP for mammography and then Pap smear screening.)

Connie: A mammo-what? I don’t know what you are talking about.

LHA: (Advise based on what Connie told you and then ask about Pap smear screening.)

Connie: Of course I get a Pap smear. What woman wouldn’t? The doctor automatically does it when he checks me down there.

LHA: (Advise based on what Connie told you.)

Need-A-Hand Natasha

LHA: (Introduce yourself to "advisee" and try to figure out STEP for mammography and then Pap tests.)

Natasha: I should get one but it's such a hassle! You'd think that the doctor's office, of all places, would have an entryway big enough for my wheelchair. But, I always have a time getting in and out. Plus, I would have to find a friend to go with me. And she needs to be a GOOD friend – someone I wouldn't mind asking to help me get my clothes on and off. And she better be strong too! It's hard work to get me up out of this chair and to keep me propped up in front of that machine.

The one time I had a mammogram, the lady wasn't very nice about calling an aide to help me stand. Then she complained that the films weren't good quality because I wasn't in a good position. I'm not sure she ever got what she needed.

LHA: (Advise based on what Natasha told you and then go on to ask about Pap smear screening.)

Natasha: Yeah, I know I should get a Pap smear, but getting onto the exam table – it's a nightmare! Ha! I'd rather have a mammogram and you already heard what I think about those!

Practicing Penny

LHA: (Introduce yourself to “advisee” and try to figure out her STEP for mammography screening.)

Penny: I just got my Pap smear last week. I was really scared that it would hurt real bad but I realized that not knowing if I had cervical cancer could hurt way worse.

LHA: (Advise based on STEP.)

Mixed Melanie

LHA: (Introduce yourself to “advisee” and try and figure out STEP for mammography first and then Pap smear screening.)

Melanie: I have my mammogram every year. Breast cancer is such an important issue for all women my age. I used to worry about the pain but now I take Advil before I go and don’t even think twice about it.

LHA: (Advise based on what Melanie said and then ask about Pap smear screening.)

Melanie: What’s a Pap smear? Isn’t that the test a doctor does to look at the uterus? Why would I have that? I’ve got nothing to worry about- I’m not that kind of woman.

LHA: (Advise based on what Melanie told you.)

Breast and Cervical Health
Session 4

Agenda

- **Arrival/Gathering** (20 minutes)
- **Review/Preview** (15 min)
- **Ice Breaker: Who Can Help?** (15 min)
- **Health Care Providers** (15 min)
- **Provider Puzzle** (10 min)
- **Financial Resources** (30 min)
- **Other Resources** (10 min)
- **Role Plays** (20 min)
- **Survivor Panel** (25 min)
- **Closing/Evaluation** (30 min)

Learning Objectives

- **Learn about financial resources cancer screening**
- **Learn about transportation, information and support resources**
- **Be more aware of needs and services that are relevant to women with disabilities**
- **Be more aware of the experiences of breast cancer survivors**

Total Time

3 hours, 10 minutes plus 10-minute break

Handouts

- **Post-workshop survey (#4A)**
- **Community-specific resources brochures**

Flipchart templates

- **Health care provider list**
- **Head, Heart and Feet drawing**

Trainer's Notes	

Arrival/Gathering

Trainers:

Time: 20 minutes

Background: The workshop incorporates 20 minutes for arrival, sign-in, and gathering. At the end of the 20 minutes, participants should be gathered at the table and ready to begin the workshop.

Training Objectives:

At the end of this activity trainers will have:
1. Completed logistical aspects of the workshop.

Materials:

- Name tags
- Pens
- Sign-in sheet
- Refreshments

Steps:

1. Make sure the room is set up before participants begin arriving.
2. Have person(s) greet participants as they arrive.
3. Have table with registration materials clearly displayed. Have all participants sign in and put on name tags when they arrive.
4. Encourage participants to eat and mingle.
5. Inform participants 5 minutes before the start of the session activities so they can begin gathering at the table.

Trainer's Notes	

Review/Preview

Trainers:

Time: 15 minutes

Background:

Training Objectives:

At the end of this activity trainers will have:

1. Started the workshop with a safe and comfortable atmosphere.
2. Reviewed the ground rules and added to them if necessary.
3. Reviewed and addressed wishes from session 3.
4. Reviewed what was covered in session 3.
5. Addressed any questions or concerns regarding session 2 material.
6. Introduced the agenda and learning objectives for session 4.

Materials:

- Ground rules
- Parking lot
- Pluses and wishes from session 3
- Session 3 learning objectives
- Session 4 agenda
- Session 4 learning objectives
- The three stage characters: 1) Susie STOP 2) Yasmin YIELD 3) Greta GO

Steps:

1. Welcome participants to the session. Acknowledge any new observers, guest trainers, etc.

2. Open the session with a prayer led by one of the participants.

    - Let's begin our final session together with a prayer. Today _____ is going to lead us in the opening prayer.

3. Remind participants of the ground rules that were created in the first session. (The list should be posted in the room where everyone can see them). Have a participant read the list aloud to the group. Ask the group if they have any questions, changes, or additions to make to the list.

4. Post Pluses and Wishes from previous session. Acknowledge the pluses and explain which Wishes were addressed and how.

- I appreciate the feedback you gave about the last session. These are some of the things that people liked about that session...(list a few pluses).

- Some of the suggestions that were made for improving the session were…(list wishes). We could accommodate these requests (list) by doing (…). However, these requests were beyond the scope of the workshop.

- Thank you again for the feedback. We tried to address as many as possible to meet your needs.

5. Review key messages from Session 3.

   - Let us take a look back at what we did last session. Last session we…(read learning objectives). Because we introduced a lot of important concepts about advising, I want to briefly review some of those concepts.

6. Divide the room into thirds and distribute one of the three stage characters to each section. Ask each section to tell the group which stage of change their character represents and something they might say to a woman at that stage. Prompt with clues: Witness, Light the Way, Praise.

   Some sample responses might include:

   - Susie STOP: She is not thinking about getting screened. Witness with factual information.
   "Screening tests find cancer early when it is most successfully treated." "All women over 40 should get a mammogram." "All women need a Pap test whether they are sexually active or not."

   -Yasmin YIELD: She is thinking about getting screened. She has some knowledge, but is not acting on it. Light the Way with informational support.
   "You can get your breast exam and Pap smear at the health department and Medicare covers the cost." "I'm going to the doctor's office next Thursday for my check-up. Call for an appointment and we can ride together." "There are funds available through the health department for your breast exam and Pap smear if you don't have insurance and meet the guidelines." If physical limitations are keeping her from scheduling an appointment, you might say, "Let's call and request an extended appointment in case you need extra time preparing for the exam." Or "When you call the clinic, ask if they have an exam table that accommodates women who use wheelchairs."

   -Greta GO: She is ready to go or has gone for screening tests. Praise the action and reinforce.

	"I'm so glad you made an appointment for your breast exam and Pap smear. You mean a lot to me and I want you to be healthy." "Now that you've gotten your screening tests done, don't you feel better knowing you're ok?" 7. Review the Session 4 agenda and learning objectives. Post on wall. ♦ Now let's look at what we're going to do today. Today we will: - Learn about different health care providers / practitioners in the community -Identify which providers / practitioners can provide a clinical breast exam, Pap smear screening, mammograms, and mammogram referral. -Become familiar with resources in the community for sharing information with women who need services. -Become more aware of the experiences of women with disabilities. -Become familiar with financial resources for clinical breast exams, Pap smears, mammograms and follow-up services. -Become familiar with transportation resources in our communities. 8. Acknowledge parking lot. ♦ As promised, the parking lot is here to keep track of concerns that come up which we cannot address immediately. We will mark off items as they are discussed. 9. Lead into next activity. ♦ Now let's move on to an activity that will get us warmed up for today's session on health care resources.

Trainer's Notes	

Ice Breaker:
Who Can Help?

Trainers:

Time: 15 minutes

Background:

Training Objectives:

At the end of this activity trainers will have:

1..Raised awareness among participants that finding resources and knowing where to go are challenges that women in the community face.

2..Helped participants understand the feelings of frustration and concern that may arise when women have health care needs and don't know where to go to address them.

Materials:

- 10 cards containing information about needed resources:
  - -you have a dog that needs shots
  - -your hot water heater is leaking
  - -you need your tires rotated
  - -your granddaughter needs immunization shots
  - -your electricity hasn't come back on after the big storm
  - -you need to have your hair done for your daughter's wedding
  - -you need help with your income taxes
  - -you need to make an alteration to a dress that is too long
  - -you need a zip code for another city
  - -you want to learn first aid
- 10 cards containing answers to needed resources
  - -vet
  - -plumber
  - -auto mechanic
  - -pediatrician
  - -electrician
  - -beautician
  - -accountant
  - -seamstress
  - -post office
  - -Red Cross

Steps:

1. Explain activity.

- This activity will help demonstrate what it is like to have to find help or resources in our everyday lives. Each person is going to get a card that will have either a question or an answer on it. For every person with a question, someone will have her answer. The idea is to ask around until you find the person that is your match, so that the people with questions actually get their questions answered. You will have 3-5 minutes to find your match. I will sound a chime to let you know when time is up.

2. Randomly distribute Question and Answer cards to participants. Be sure for every Question card distributed the appropriate Answer card is also distributed.

3. After the time is up and all Questions and Answers have been matched up, discuss what it was like to participate in this activity. Ask the group members:

   - How did it feel to have a need and have to wander around and talk to several people to find your answer?
   - How many people did you have to ask before you found your answer?
   - How did it feel to have an answer and not know who needed it.
   - How many people came to you for help but you weren't the right resource?

4. Link to next activity.

   - The feelings you expressed from this activity may be how a woman feels when she knows she needs to have a breast exam or Pap smear, but doesn't know where to go. Or how a health care provider may feel when he or she knows there are women who need services, but don't know who they are. Today's session on resources will touch on five areas that will help prepare you to match up women and resources in your community. It takes knowledge of all five areas to be a successful Lay Health Advisor.

Trainer's Notes

Health Care Providers for Breast & Cervical Cancer Screening

Trainers:

Time: 15 minutes

Background: Health care professionals make up one of our five important resource elements. Many health care professionals in a community can provide basic breast and cervical cancer screening services. This section explains who the different health care providers are and how they differ from one another. A woman can then choose a provider to meet her needs.

Training Objectives:

At the end of this activity trainers will have:

1. Presented the different health care disciplines and which services they can provide.
2. Presented the various health care providers in the community who can meet the needs for clinical breast exam, Pap smear and referral for mammography.

Materials:

- Flipchart with list of types of health care providers that perform CBEs, mammograms, and Pap smears
- Blank flipchart pages
- Markers
- Brochures with county-specific provider information

Steps:

1. Using a flip chart with different health care providers listed, introduce participants to the various health care providers that a woman may come into contact with if she has a Pap smear, clinical breast exam, or mammogram.

    ♦ There are many different types of providers that can perform Pap smears, clinical breast exams, mammograms, or refer a woman for a mammogram. These include:
    -Family Practice
    -Internal Medicine
    -OB/GYN
    -Physician Assistants
    -Nurse Practitioners
    -Radiologists (mammography only)
    -Radiology Technicians/Technologists (mammography only)

- Let's discuss the differences and similarities between the providers.

2. Use one flipchart page to write the names of specific providers in the community and where they work.

Family Practice

- General Practice is an older term for the community doctor who would see all the members of a family. In 1969, the classical practice of general medicine was changed to **Family Practice** (write on flip chart). Family Practice and General Practice doctors care for the entire family from providing prenatal care to caring for aging elders. They provide check-ups or physicals, prevention care such as immunizations, and sick care. Family Practice doctors can perform both clinical breast examinations and Pap smear screenings and refer women for mammograms.

- Who can name a family practice doctor in this community? Where do they work?

Internal Medicine

- An internal medicine doctor or "Internist" is a physician who specializes in the prevention, diagnosis and medical treatment of adults. Internists, like Family Practice doctors, can perform both clinical breast examinations and Pap smear screenings and refer women for mammograms.

- Can anyone name an Internal Medicine doctor in this community? If a woman wanted to make an appointment with them, where would she call?

OB/GYN

- OB/GYN is a commonly-used abbreviation. OB is short for obstetrics or for obstetrician, a physician who delivers babies. GYN is short for gynecology or for a gynecologist, a physician who specializes in treating diseases of the female reproductive organs. An obstetrician/gynecologist (OB/GYN) is therefore a physician who both delivers babies and provides treatment and preventive care that relates to female reproductive organs. They also can perform both clinical breast examinations and Pap smear screenings and refer women for mammograms.

- Are there any OB/GYN doctors in this community? Who are they? Where do they work?

- Most adult women see a family practitioner, an internist or a gynecologist. But, some women with chronic conditions see one or more specialists. Since a specialist is focused on treating specific diseases or conditions they may not consider recommending

mammograms, clinical breast exams or Pap screening. A woman who receives her care from a specialist should request a screening recommendation. Otherwise she may not receive a referral.

Physician Assistants

- Physician assistants, also called PAs, are well-trained health care providers who work for and under a physician. A physician assistant or PA can perform treatments for illness, do physicals and exams, and prescribe some medications. A physician assistant may perform both clinical breast examination and Pap smear screening and refer for a mammogram.

- Who are the physician assistants who work in this community? Which doctors do they work with?

Nurse Practitioners

- Nurse practitioners are nurses who have additional education beyond their RN and work with physicians providing some of the basic services patients need. Among other things, a nurse practitioner can perform physicals including clinical breast examination and Pap smear screening. They can also refer for mammography. Some nurse practitioners are called Family Nurse Practitioners (FNP) or Clinical Nurse Practitioners (CNP) depending on their specialized training.

- Who are the nurse practitioners in the community? Where do they work?

Radiologists

- Radiologists are physicians trained in the specialty of reading x-rays and other imaging tests (CAT scan, MRI). Radiologists can specialize in reading x-rays of the breast. Radiologists can perform mammograms but not Pap smears or clinical breast exams.

- Can anyone name radiologists who work in this community? Where do they work?

Radiology Technicians/Technologists

- Radiology technicians have had 2 or 4 years of training and are skilled in taking x-rays and other imaging tests. Technicians who perform mammography receive special training. The facility where the mammogram is done must meet national standards for equipment, training of technicians, and have radiologists who can read the pictures.

3. Tie in homework assignment from last session (finding out where a woman can get a mammogram or Pap smear). Trainer should allow

participants to share information from their homework until all the different resources they found have been shared.

- Now let's see if any of you found some additional information to share from your homework assignment. The assignment was to gather information about where a woman can go to get a mammogram or Pap smear in your community. Who would like to share some of the information they found?

4. Address the issue of physician referral.

   - Physician referral is required for mammography in some places because the radiologist who reads the x-ray needs some place to send the results. If a woman needs follow-up services, the radiologist could perform additional tests, but would not be the appropriate health care provider to meet all of her medical needs.

   - Where would a woman have to go if she needed a referral for a mammogram?

5. Return to flip chart page with all providers listed. Link to next activity.

   - As we can see, there are a lot of different people who are qualified to perform Pap smears, CBEs, and mammograms for women. To try and understand all this information better, let's do an activity that will allow us to practice using our knowledge about health care providers.

Trainer's Notes	

Activity – Provider Puzzle

Trainers:

Time: 10 minutes

Background: This activity allows the participants to begin viewing health care providers as tangible resources in the community.

Note to trainer: This activity is a <u>great</u> energizer. Be sure to include it!

Training Objectives:

At the end of this activity trainers will have:

1. Reinforced the idea that finding the health care provider you need may be challenging.
2. Provided an opportunity to apply knowledge about the different health care providers who can provide services for clinical breast examination and Pap smear screening.

Materials:

- Community resources puzzle pieces

Steps:

1. Explain activity.

    - ♦ To help us understand better all the places a woman can go and the providers she can see to get a Pap smear and mammogram, we are going to put together a puzzle of health care resources.

    - ♦ We have a number of different puzzle pieces. Each piece represents a health care provider in the community. By putting the puzzle together, we will have a picture of all the women's health services in the area.

2. Distribute pieces of Resource Puzzle to participants.

3. Have group work together to assemble puzzle.

4. Have a few participants share some of the differences between health care providers and which ones can provide clinical breast examination, Pap smear screening, referral for mammograms and mammogram services.

    - ♦ Of the health care providers in our puzzle, which ones can provide Pap smear screening? Which ones perform clinical breast exams? Which ones can provide mammography? Who can give a referral for a

	mammogram? 5. Link to next activity. ♦ Now that we know how to help women who do not know where to go to get a Pap smear or mammogram, we need to look at the second important community resource - financial resources. Knowing about the financial resources available in our community can help us advise women for whom these screening tests could be a financial burden. ♦ Before we start the next activity, let's take a 10 minute break.

B R E A K

Trainer's Notes

Financial Resources

Trainers:

Time: 30 minutes

Background: There are some standard sources of insurance and financial aid for women to get cancer screening tests. The 4 main sources of payment for doctor's office visits and mammogram screening are: Commercial Insurance, Medicaid, Medicare Part B and Federal Breast and Cervical Cancer Control Program (BCCCP) funds Other financial assistance may be available through NC Cancer Fund and local religious charities.

The information written up in this section should be used as talking points by the speaker and not covered in its entirety. It is recommended that the speaker present general information about financial resources, then leave time to answer more specific questions from the participants. It is important to supplement this section with the community specific resource handout (Greensboro Community Resource Guide for Breast Cancer).

Trainers should meet with guest speakers beforehand to discuss the purpose, format, and content of the session.

Training Objectives:

At the end of this activity trainers will have:

1. Presented the major financial resources for clinical breast exam, Pap smear, and mammography.
2. Presented some of the guidelines to qualify for healthcare financial support.

Materials:

- Brochure with community specific information (i.e. Greensboro Community Resource Guide for Breast Cancer)

Steps:

1. Introduce guest lecturers.

    - ♦ We are now going to discuss the financial resources that are available to women to help pay for mammography and Pap smear screening. To lead this discussion we have some very special guests. Please welcome _____ (name of guest trainers).

Talking points to be included in the presentation:

Medicare

- Medicare is our country's health insurance program for people age 65 and older who are eligible for SS benefits (having worked and paid into the system. People under age 65 with disabilities may also be eligible for Medicare.

- Medicare has two parts – Part A and Part B

  - Part A is hospital insurance and helps pay for inpatient care in a hospital, skilled nursing facilities, or hospice care. It also pays for limited home health care.

  - Part B is medical insurance and helps pay for doctor's services, medical services, outpatient care, x-rays, and other lab tests and supplies

- Everyone is eligible for Part A at no charge. For Part B you pay a monthly premium of $50.

- Part B covers 80% of allowable costs for mammograms and Pap smears
  - Mammograms once every two years (including for women with disabilities who are 50-64 yrs old)
  - Diagnostic or follow up mammograms as needed
  - Pap smears, including a pelvic exam and clinical breast exam, once every three years (For a woman at high risk for cervical cancer, it covers screening once a year.)

- Medicare Supplement insurance pays remaining 20%

- If no supplemental insurance, patient is responsible for remaining 20% balance.

- For example: Radiology Center charges $85 for routine screening mammogram. Medicare limits payments for routine mammogram to $69.23.

  Provider writes off difference between $85 & $69.23 ($15.77)

  Medicare pays provider 80% of $69.23 $55.38
  Supplement or patient pays 20% balance $13.85

- If a health care provider is approved as a Medicare provider, they cannot bill for more than the Medicare approved amount. Nor can they limit the number of Medicare patients they serve. They can bill patients for the 20% balance.

- For access to Medicare– Call the Social Security Administration toll free at 1-800-772-1213 or your local Social Security office for information about how to receive Medicare.

- Department of Social Services also has programs for low income adults who do not qualify for Medicare A and to assist with the premium payments for Medicare Part B
  - MQB-Q program (or Comprehensive Medicare-Aid) pays the Medicare Part A and B monthly premium, Medicare deductibles, and co-insurance.
  - MQB-B (or Limited Medicare-Aid) program and the MQB-E (Limited Medicare-Aid Capped Enrollment) program both pay the Medicare Part B monthly premium.
  - MQB-QI2 (Medicare Aid Partial Reimbursement) program pays a portion of the Medicare Part B premium (currently in the form of a check at the end of the year.)
  - MWD pays the Medicare Part A premium for disabled individuals who have lost eligibility for Medicare Part A due to earnings greater than the amount allowed by the Social Security Administration.

Medicaid

- Medicaid is a state-administered insurance program funded by federal and state tax dollars that provides coverage for eligible, low-income persons

- Eligibility requirements are based on age or disability and income.

  - **Age** 65 or disabled as defined by the Social Security Administration

  - **Income** Limited monthly income (as of April 1, 2001)

Family size	1	2(married couple)
Monthly income limit	$716	$968

    If monthly income exceeds these amounts, the person must meet a deductible based upon a federal formula. All doctor, hospital and prescription costs incurred can be added up to meet the deductible. Once the deductible is met, then Medicaid benefits can begin.

- Medicaid covers
  - Screening mammograms
    - Age 35-39 one mammogram within 5 years
    - Age 40-49 one mammogram every year
    - Age 50-65 one mammogram every year

- Age 65+ one mammogram every other year
- More frequently with medical necessity

- Diagnostic or follow up mammograms as needed
- Pap smears once every 365 days or more frequently when medical necessity indicates or with certain medical diagnoses

♦ If a health care provider is approved as Medicaid provider, then they must accept the payment schedule published by Medicaid and cannot bill the patient for any difference between the approved rate and the normal cost.

♦ For access to Medicaid, contact local Department of Social Services (DSS) for information.

Breast and Cervical Cancer Control Program (BCCCP)

2. If different from previous speaker then:

♦ Now I'd like to introduce _____ from the health department's Breast and Cervical Cancer Control Program. _____ is a *name position such as nurse/eligibility specialist* who will tell us about a federal program we have available in our county.

Talking points to be included in the presentation:

BCCCP

♦ BCCCP is a federally-funded program that gives money to county health departments and rural health centers so that they can provide mammograms and Pap smears to low and moderate income women.

♦ BCCCP covers (*new guidelines due out in April 2001*)
- Mammograms
- Pap smears
- Initial follow-up visit for abnormal results

♦ Eligibility requirements
- 50 – 64 years of age (up to 25% of women served can be 40-49 years old)
- no health insurance, Medicare Part B or Medicaid
- income at or below 200% of poverty level
  - 1 person < $16,700/yr
  - 2 persons < $22,500/yr
  - 3 persons < $28,000/yr
  - 4 persons < $34,100/yr

- 5 persons < $39,900/yr
- 6 persons < $45,700/yr
- 7 persons < $51,500/yr
- 8 persons < $57,300/yr
- for each family member over 8 add $5,800

- For BCCCP to pay for a mammogram, there must be appropriate documentation of the following tests within the previous two months:
  - Clinical breast examination
  - Pap smear
  - Pelvic examination
  - Blood pressure measurement
  - Instruction on breast self-examination

♦ Access
- In some counties private doctor's offices and clinics coordinate with the health department for patients seen outside the health department to have Pap smear appointments and mammogram paid for by BCCCP funds. Some counties use the BCCCP funds for mammogram payments only.

Guilford County Health Department

BCCCP Coordinator- Guilford County, Shirley Spencer, RN
336-641-3233
This BCCCP program provides free screenings for breast and cervical cancers. Funds are used for eligible women who are below poverty level and who are having immediate breast issues. A woman must be a part of the program BEFORE she is diagnosed with breast cancer. BCCCP has partnered with Piedmont Health Services and Sickle Cell Agency to provide a bi-monthly screening clinic to conduct clinical breast exams on women who meet the eligibility criteria., in addition to providing a instruction and learning session on breast self-examination for those women who do not meet the eligibility criteria.

Private insurance

NC General Statute Chapter 58, Article 51, Section 57 Since January 1, 1992, NC has required all providers of accident or health insurance who are licensed to write policies in NC to provide policy holders with coverage for mammograms and Pap smears.

♦ **Mammograms**

- Coverage for low-dose screening mammography shall be provided as follows: (1) One or more mammograms a year, as recommended by a physician, for any woman who is at risk for breast cancer.
- One baseline mammogram for any woman 35 through 39 years of

age, inclusive;
- A mammogram every other year for any woman 40 through 49 years of age, inclusive, or more frequently upon recommendation of a physician; and
- A mammogram every year for any woman 50 years of age or older.
- Reimbursement for a mammogram authorized under this section shall be made only if the facility in which the mammogram was performed meets mammography accreditation standards.

♦ **Pap Smears**

- Coverage shall be provided for Pap smears obtained once a year, or more frequently if recommended by a physician. Coverage shall include the examination, the laboratory fee, and the physician's interpretation of the laboratory results.

- **Project Access of Greater Greensboro** (336) 235-0930
1050 Revolution Hill Drive, Studio 4, Greensboro, NC 27405
Project Access of Greater Greensboro is a program that provides medical insurance for the uninsured/underinsured in Greater Greensboro (all Guilford County except High Point). The program provides services for adults (19 years or older). Project Access assists patients with the coordination of their healthcare needs, assistance with dental and eyeglass prescriptions, assistance with medications, mental health assistance and interpretation services. Specialty Care Physicians, donate their services to Project Access Patients. Patients receive a primary care physician, and case managers work with patients in understanding their chronic illness and adhering to the plan of care prescribed by the physician.
Days of operation: Monday - Friday
Hours of operation: 8 a.m. - 5 p.m.
Population served: Uninsured Adults (19 years or older)

- **HealthServe** (336) 271-5999, ext. 338 or 322
1002 S. Eugene Street, Greensboro, NC
Contact Wanda McGee at **wanda.mcgee@mosecone.com**
This program provides medical attention and prescription assistance to people who are a part of the HealthServe system.
Days of operation: Monday - Friday
Hours of operation: 8 a.m.- 1 p.m. and 2 p.m.- 5 p.m.
Population served: Patients who are a part of the HealthServe system.

- **Women's Hospital of Greensboro Center Mammography**
801 Green Valley Road, Greensboro, NC

- **American Breast Cancer Foundation** 1-877-539-2543
www.abcf.org

Sponsors the "Key to Life" Breast Cancer Early Detection Program, which offers clinical breast exams, mammograms, and ultrasound free of charge to eligible women. Uninsured and underinsured women of all ages are interviewed to determine their needs and first referred to government programs if they fit those criteria.

- **"ENCORE Plus" of the YWCA of Greensboro** 336-273-3461
  YWCA Place, Greensboro, NC 27405 www.ywcaofgreensboro.org
  Provides free or low-cost clinical breast exams, mammograms and pap smears to women with certain incomes. Also provides educational seminars, breast self-exam training, and peer group support and exercise.

- **North Carolina Cancer Assistance Program**
  919.707.5321 or 866.693.2656
  North Carolina Division of Public Health
  Provides financial assistance for diagnostic or treatment services to qualified applicants. Applicants must be North Carolina residents, meet financial and certain medical requirements. Patient's doctor must submit a letter for the patient. Services must be pre-approved; there is a maximum per pre-approved claim of $25,000. The program approves up to 8 days of service for the diagnosis of cancer per year.

Free Screening Days

Present any information regarding free screening days that may be offered in the community.

- **Piedmont Health Services and Sickle Cell Agency** offers a bi-monthly clinic for free clinical breast exams and to women who meet the eligibility criteria. The clinics are held on the 2nd Friday of each month at 1102 Market Street, GSO and on the 4th Fridays of each month at 401 Taylor Ave, HP. Persons are seen by appointment only.

3. Draw discussion to a close and thank guest speakers.

   ♦ Thank you very much for being here with us today and helping us understand the financial resources available to women in our county. It will be very important for our LHAs to share this information with women who are concerned about the cost of getting a mammogram.

   ♦ I know this was a lot of information, so at the end of the session today we will be providing you with a brochure that summarizes it for you.

4. Link to next activity.

   ♦ Health care providers and financial resources aren't the only resources

	it's important to know about as an LHA. Next, we're going to briefly talk about other resources that can make it easier for women to get a mammogram or other information about breast cancer.

Trainer's Notes	

Other Types of Resources

Trainers:

Time: 10 minutes

Background: The presence of adequate health care provides and knowledge of financial resources to pay for care are only two of the five important community resources Lay Health Advisors need to know about. Other important resources for women are to know about are where to get information, transportation and support.

Training Objectives:

At the end of this activity trainers will have:

1. Discussed information and transportation resources for CBE, Pap smear, and mammography.
2. Presented guidelines for qualifying for each service.
3. Described support services for patients who have had an abnormal mammogram or cancer diagnosis

Materials:

- Brochure with community specific information (i.e. Greensboro Community Resource Guide for Breast Cancer)

Steps:

1. Pass out resource brochure and refer to it during the following discussion.

2. Reinforce the resource of Community Outreach Specialists to the community.
   - ♦ One resource we may not think of as a resource is the Community Outreach Specialist. You may hear us refer to the Community Outreach Specialist as a COS. COSs are women who have been working in this community and have had the opportunity to learn more about breast and cervical cancer to be community resources. COSs may not know all the answers to your questions, but they know how to find out. They have the resources of UNC Lineberger Comprehensive Cancer Center as well as the National Cancer Institute and American Cancer Society to draw upon.

Information resources

- Community Outreach Specialists (COS) for Guilford County
  - o (_____) **Place phone number in blank**
- American Cancer Society 1-800-227-2345
- National Cancer Institute 1-800-4 -Cancer

- CARELINE -1-800-662-7030
- United Way 211

Transportation resources

- ***SCAT-Greensboro Transit Authority***
  320 E. Friendly Avenue, Greensboro, NC 27401
  Contact person: Sherria High
  Phone: (336) 373-2166 **Fax:** (336) 373-2809
  This program provides door-to-door and curb-to-curb service for persons with disabilities.
  Days of operation: Seven days a week
  Hours of operation: 5:15 a.m. - 12:30 a.m. (Weekdays).
  6 a.m. - 11 p.m. (Saturday).
  6 a.m. - 7 p.m. (Sunday).
  Population served: Cancer patients.
  Is there a cost for the program? Yes. $1.10 each way or a 10 ride punch card for $10.
  ** Prior to using this program you must complete a SCAT application. This application process can take up to 21 days.

- ***"Road to Recovery" A Program of the American Cancer Society***
  501 N. Elam Ave., Greensboro, NC 27403
  Contact person: ACS - Cancer Information Specialist
  Phone: 1-800-227-2345
  Volunteer drivers provide cancer patients transportation to and from their scheduled medical appointments for treatment.
  Days of operation: On an as needed basis
  Hours of operation: On an as needed basis
  Population served: Cancer patients
  Is there a cost for the program? No
  Does this agency require a referral? No

Breast cancer support groups

- ***Regional Cancer Center***- Breast Cancer Support Group
  501 N. Elam Avenue, Greensboro, NC 27403
  Contact person: Terry Moore-Painter
  Phone: (336) 832-0364
  This program provides support for women who are newly diagnosed, undergoing treatment, or who have concluded treatment for breast cancer. Laura Herring, a licensed psychologist, facilitates the group.
  Days of operation: Third Tuesday of each month
  Hours of operation: 7 p.m.

- ***Regional Cancer Center***-Young Women's Breast Cancer Support Group
  501 N. Elam Avenue, Greensboro, NC 27403
  This program provides support to women under the age of 40 with any stage of breast cancer, during and after any point of their cancer

treatment.

Days of operation: Fourth Monday of each month
Hours of operation: 7 p.m.

- ***Encore PLUS***
  A program conducted in cooperation with the YWCA of Greensboro.
  1 YWCA Place, Greensboro, NC 27401 (behind the Public Library on Church Street).
  Phone: (336) 273-3461
  This is a multifaceted program serving women with breast cancer or breast cancer survivors. This program offers support group sessions as well as physical activity, primarily swimming.
  Days of operation: Tuesdays and Thursdays
  Hours of operation: Tuesdays, 9:30 - 11 a.m., and Thursdays, 10 - 10:45 a.m.

- ***Reach to Recovery*** A Program of the American Cancer Society.
  4A Oak Branch Drive, Greensboro, NC 27407
  Phone: 1-800-ACS-2345
  Newly diagnosed breast cancer patients are matched with breast cancer survivors in a mentoring relationship according to age. Currently, there are a number of breast cancer survivors waiting to mentor.
  Days of operation: Varies from volunteer to volunteer.
  Hours of operation: Varies from volunteer to volunteer.

- ***Look Good, Feel Better*** A program of the American Cancer Society
  Classes take place at the Regional Cancer Center.
  Contact person: ACS Cancer Information Specialist
  Phone: 1-800-ACS-2345
  Once a month, a licensed cosmetologist conducts an information session where women with breast cancer are given a free skin care kit. In addition, the cosmetologist discusses changes of the hair and skin during chemotherapy and radiation.
  Days of operation: Varies. Program takes place once a month.
  Hours of operation: Varies. Program takes place once a month.

- ***Women's Resource Center of Greensboro, Community Resource Counseling Program***
  628 Summit Avenue, Greensboro, NC
  Phone: (336) 275-6090
  This program provides individual resource counseling for women faced with life transitions and crises. Trained volunteers support and assist women in accessing community resources. Clients create an action plan and learn how to obtain resources most effectively and efficiently which will help them resolve these issues.
  Days of operation: Monday and Wednesday from 9 a.m. to 5 p.m. and Tuesday and Thursday from 10 a.m. to 7 p.m. Counseling appointments can be made during any of these hours

and are dependent upon the availability of volunteer counselors.
Hours of operation: See above.

- ***Hospice and Palliative Care of Greensboro, The Counseling and Education Center***
  2500 Summit Avenue, Greensboro, NC
  Phone: (336) 621-5565
  This program provides individual bereavement counseling and community education programs on grief and loss. The staff at the Counseling and Education Center consists of licensed, clinical social workers. One staff member has a doctorate in divinity.
  Days of operation: Monday-Friday 8:30 a.m. - 5 p.m.
  Hours of operation: Counseling and educational seminar times vary based on need. Please call for specific information regarding your personal needs.

- ***Kid's Path***
  2504 Summit Avenue, Greensboro, NC
  Contact person: Meghan Davis, Assistant Director
  Phone: (336) 544-5437
  This program provides one-on-one and group counseling for children and teenagers coping with the illness or loss of a loved one.
  Days of operation: Monday - Friday
  Hours of operation: 8:30 a.m. - 5 p.m. (after hours available based on individual client need)
  Does this agency require a referral? No
  Is this agency accessible via the GTA? Yes

- ***Pink-Link***
  149 S. Barrington Ave., #734, Los Angeles, CA 90049-3310
  Phone: (310) 995-5204
  This is a nonprofit organization that connects breast cancer patients with breast cancer survivors. Survivors provide detailed descriptions of their breast cancer issues in the Pink-Link database. A newly diagnosed patient can search this web site information and request to connect with someone who has been there herself. In addition, other support programs included on the web site are a planning organizer to help with driving, dinners, etc. and a personal journal one can share with family and friends (a blog).
  Days of operation: Monday - Sunday
  Hours of operation: N/A
  Population served: Women with breast cancer of any age and stage of cancer.

3. Summarize information on resource brochure is for LHA use. Note that it is not designed for distribution to community members.

   ♦ As you can tell from these discussions today, there are a lot of

	resources out there for women who need information, financial aid, or other types of support related to breast cancer and mammography. For your specific county, we've summarized the resources available in a brochure. Hopefully, you can keep this with you and use it if you're speaking with a woman who needs a particular resource. ♦ In the next activity, we'll practice doing just that.

Trainer's Notes	

Resources Role Plays

Trainers:

Time: 20 minutes

Background: The purpose of this activity is to provide participants an opportunity to apply the information learned throughout the training sessions. As before, scenarios will be designed so that participants can practice identifying a woman by her stage of change and deliver a corresponding stage-appropriate message. For this final role play session, some of the scenarios will be designed so that LHAs can practice advising women on financial and transportation barriers as well. Scenarios might also include LHAs working together to plan an event for which they need additional information or cancer-related materials.

Training Objectives:

At the end of this activity trainers will have:

1. Helped participants apply the concepts learned throughout the training session.
2. Facilitated discussion about how participants integrate information about community resources into their advising.

Materials:

- Role plays (2 copies of each scenario)

Steps:

1. Have volunteers read role of LHAs in scenarios. Facilitator will play part of "advisee". Use the following discussion questions after each scenario is acted out.

    - Based on her comments, what STAGE (Go, Yield, Stop) was this woman in her decision-making to get a mammogram or Pap smear?

    - Which kind of advising (Praise, Light the Way, Witness) is most appropriate for this woman.

    - What kind of information does this woman need:
        a. Basic information about breast health
        b. Specific information about mammogram or Pap smear
        c. Resource information on healthcare providers, financial resources or transportation.

Role Play #1: Jobless Janice

LHA: (Sees a woman from her neighborhood at the post office) "Hi, Ellen. I heard you quit work recently. Are you enjoying your free time?"

Ellen: "Enjoying? I've spent more time at the doctor's office this past year than ever. That's why I had to quit working. I'm not going to enjoy paying all those doctor bills now that I'm not working. And my doctor just told me to go get a mammogram. How am I going to pay for that now?"

LHA: "It is still important for you to keep that mammogram appointment and I'm glad you plan to go. Since you lost your insurance from your job and you're not old enough for Medicare, there may be some other groups that can help pay for your mammogram. Have you talked to social services to see if you are eligible for benefits under the state Medicaid program? I also know that the health department has federal funds to pay for mammograms for women who don't have health insurance or Medicaid. A call to the health department – *name specific BCCCP coordinator* – might be just what could help you out."

STAGE: Yield (almost a GO, but financial barrier causing hesitation)
ADVISING: Light the Way, reinforce the positive intentions and give the next step of encouragement.
INFORMATION NEEDED: Resources for financial assistance

Role Play #2: Caring Clara

Clara: "Hi,_____. I'm glad I ran into you today. My Aunt Bessie got a call from her doctor telling her she had to go back for another test because her Pap smear was abnormal. Her appointment isn't until next week and she is worried because she doesn't know what that means, and how much all this might cost. I'm afraid she won't go."

LHA: "I hope you will encourage your Aunt Bessie that she really needs to keep her doctor appointment about her abnormal results. Until she talks to the doctor, she doesn't know what she's dealing with. Does your Aunt know that cervical cancer is treated easily when it is detected early?"

Clara: " I don't think she has much information on cervical cancer. She asked me if I had any of those materials you were giving out at the health fair."

LHA: "I have some in my car that I can give you right now. Also, if your Aunt Bessie is eligible under the income guidelines, there are funds available through the health department to pay for follow-up appointments for abnormal Pap smears. Some women don't want their business known, but if Aunt Bessie would like to talk with me, here is my number. I may be able to give her some

information that helps her and I will encourage her to keep that doctor's appointment. She is not alone in this."

STAGE: GO turned YIELD (hesitation and anxiety because of abnormal results)
ADVISING: Light the Way, provide encouragement and informational support
INFORMATION NEEDED: Resources about cervical cancer, abnormal results, financial options

Two additional role plays:
#3 -- Thinking Thelma

LHA: Introduce yourself to "advisee" and try to figure out STEP for mammography and then Pap smear screening)

Thelma: I'm thinking about getting a mammogram since my doctor told me I should. But she didn't tell me where to go or how much it would cost.

LHA: Advise based on what Thelma told you and then transition to Pap smear screening.

Note to facilitator: Thelma is at YIELD for mammography screening. LHA should LIGHT the WAY about BARRIERS, so LHA could describe community resources, including BCCCP, that provide assistance with the expense associated with screening. LHA can then ask about Thelma's Pap smear history.

Thelma: I've had a Pap smear before. It's been a while, though. Actually, I haven't had one since I moved to Williamston five years ago. In New York, I had the best doctor ever. He used to speak to me while he was doing the test so I wouldn't feel so funny. I know I should have a Pap but can't imagine finding anyone as nice as Dr. Stevens.

LHA: Advise based on what Thelma told you.

STAGE: YIELD (lacks knowledge about where to go)
ADVISING: Light the Way, provide encouragement and informational support
INFORMATION NEEDED: Resources about where to go and how much it costs

#4 -- Anxious Annie

LHA: Introduce yourself to "advisee" and try to figure out STEP for mammography and then Pap smear screening

	Annie: I know I should get a mammogram but I'm too nervous. They once told my friend that hers was abnormal and she had some other sort of test and everything was fine. I'd hate to go through that. LHA: Advise based on what Annie told you and then transition to Pap smear screening. STAGE: YIELD (anxiety because of abnormal results) ADVISING: Light the Way, provide encouragement and informational support INFORMATION NEEDED: Better to catch cancer early while it's still easy to treat. False positives are rare. *LHA should follow up with a question about Annie's Pap smear screening history.* Annie: It's been a while since I had a Pap smear and I would like to change that but I don't have an ob/gyn anymore. I stopped seeing her when I was done having babies. LHA: Advise based on what Annie told you STAGE: YIELD ADVISING: Light the Way, provide encouragement and informational support INFORMATION NEEDED: Resources about local providers 2. Link to survivor panel. ♦ You all are doing a great job practicing the advising skills and sharing the information you've learned in the past couple sessions. I wish we had more time to practice as a group, but we need to move on to our next activity where we will touch upon a very important aspect of breast and cervical cancer – being a breast or cervical cancer survivor. Knowing the support services that are available for breast and cervical cancer survivors is another resource that is important to share as a lay health advisor.

Trainer's Notes	

Survivor Panel

Trainers: Guest speakers

Time: 25 minutes

Background: A potential outcome of increasing the number of women who are screened for breast and cervical cancer is an increase in the number of women who are diagnosed with breast and cervical cancer. When breast and cervical cancer are detected early through mammography and Pap screening, they are easier to treat. Women who have been diagnosed with cancer, but have had it treated successfully, are cancer survivors. These women have unique concerns and experiences. This activity will allow participants to speak with cancer survivors to better understand their experiences of being screened, diagnosed, and treated for cancer.

Training Objectives:

At the end of this activity trainers will have:

1. Introduced the concept of survivorship and how it relates to mammography and Pap screening.
2. Provided an opportunity for cancer survivors to share their experiences and inform the group of support available to breast and cervical cancer survivors.

Materials:

None

Steps:

1. Introduce activity.

    - ♦ If more and more women are being screened for breast and cervical cancer, then it is likely that more cases of breast and cervical cancer will be found and more women will be diagnosed with breast and cervical cancer. This may sound bad; but, as we know, the great thing about mammography and Pap screening is that they detect cancer in the early stages while it is easier to treat. Women who are diagnosed with cancer, but get it treated successfully, are cancer survivors.

    - ♦ It is important to learn about the experiences of being a breast or cervical cancer survivor so that we can be as supportive as possible to those women.

2. Introduce survivor panel.

    - ♦ To help us better understand the experiences of a cancer survivor, we

	have some very special guests today. Please welcome (names of guests) to our session today. These women are all cancer survivors and are here today to talk with us about being a breast/cervical cancer survivor. ♦ They will begin by telling us a little bit about themselves and then they would like to take some of your questions. 3. Allow discussion on survivorship to last about 20 minutes. At the end of 20 minutes, bring discussion to a close. *(Note to trainer: make sure the discussion stays focused on breast and cervical cancer survivorship. If the group gets off track, help bring them back to the topic of interest.)* ♦ We are running out of time for our session today, so I would like to bring this discussion to a close. Let's give a big round of applause to our survivor panel to thank them for coming and talking with us today. We will give you their contact information, so you can get in touch with them if you have more questions. 4. Link to next activity. ♦ Let's now move on to the closing and evaluation for today's session.

Trainer's Notes	

Closing/Evaluation

Trainers:

Time: 30 minutes

Background:

Training Objectives:

At the end of this activity trainers will have:

1. Summarized the session activities.
2. Gathered feedback from the group about the session.
3. Reminded everyone about the graduation ceremony.
4. Encouraged participants to reflect on the workshop.

Materials:

- Flipchart
- Markers
- Session 4 learning objectives
- Session 4 agenda
- Flipchart page labeled "Similar"
- Flipchart page labeled "Different"
- Flipchart page prepared for Head, Heart & Feet
- Parking lot
- Incentive: Stoplight pin
- Graduation form
- Post-workshop surveys

Steps:

1. Introduce closing and evaluation.

    ♦ We did a lot today. Let's review what we covered today.

2. Summarize learning objectives.

    ♦ Today we…
    -Learned about resources in our community for breast and cervical cancer screening and how to help women access those resources.

3. Review the relationship between breast and cervical cancer.

    ♦ So, today we talked specifically about how resources and the health care system relate to breast and cervical cancer screening. Based on

This exercise, "Similar and Different" (# 3-4), can be omitted in the interest of time.	what we did today, is there anything we can add to our lists regarding how the two cancers are similar and how they're different? 4. Write participants responses on flipchart pages labeled "similar" and "different". <u>Sample responses for ways in which the two cancers are similar might include:</u> -Financial resources are available to help pay for both breast and cervical cancer screenings -The same providers that perform Pap smears can also refer women for mammograms <u>Sample responses for ways in which the two cancers are different might include:</u> -The providers that perform mammograms are different from the providers that perform Pap smears -Pap smears and mammograms are covered differently by different financial resources 5. Introduce "Head, Heart, and Feet." ♦ Now I want to do a special activity that will help us think back on all of the training. The activity is called "Head, Heart, and Feet." 6. Draw an outline of a body on a flipchart. Explain the activity. ♦ We have covered a lot of information and done a lot of activities. I'd like you to think about how you have reacted to the training so far. 7. Start with thoughts (head). Allow participants to think about their responses. Write responses near the head. ♦ First, what are some of the things that you are thinking about as a result of the workshop? What is some new information that you have learned? I am going to write these near the head. 8. Continue with feelings (heart). Allow participants to think about their responses. Write responses near the heart. ♦ How has the training made you feel? What feelings did you experience? I am going to write these near the heart. 9. Finish with actions. Allow participants to think about their responses. Write responses near the feet. ♦ Finally, now that you have thought and felt certain things, what are you going to do? Are you going to do anything differently? What? I

am going to write these near the feet.

10. Wrap up "Head, Heart, and Feet."

    - As you can see, the workshop has affected us in different ways. The activities and information affected our thoughts, feelings, and actions. Thank you for sharing those.

11. Review parking lot. Cross off items that were addressed.

    - Were any of the parking lot items addressed? If so, they can be marked off the list.

12. Remind participants about the graduation ceremony and ask them to fill out the graduation ceremony form.

    - The graduation ceremony is:
      Date:
      Time:
      Location:

    - I hope you all will be joining us on this special occasion. We need to keep track of how many people are coming so that we can arrange for food and space. Please fill out this form to let us know if you will be coming and how many people will be joining you.

13. Pass out and explain incentive: Stop light pin

    - To thank you for your participation today, we have one final gift for you. This is a stop light pin you can wear on your blouse or dress. It can serve as a reminder that our job as lay health advisors is to "get our sisters to go" for their mammograms and Pap smears.

14. Have participants complete the post-workshop survey (Handout #4A).

    - Another thing we need you to do today before leaving is complete a brief survey about the training. It should only take a few minutes. The trainers are going to leave the room while you fill it out. When you're finished please hand it to _____, who will give it to us. Don't put your name on the survey. We will come back after you've completed the survey to close the session.

15. Introduce closing circle.

    - It's hard to believe that we are at the end of the training. We have done a lot together. Finishing this training is a big accomplishment for everyone.

	♦ Although the training is ending, I'm excited because you all will now go forth and share the skills and information you have gained to improve the health of the women in your community. ♦ Before we have our closing prayer, I would like to do a special activity called a closing circle. 16. Ask participants to form a circle. 17. The trainer should express her appreciation for the dedication and enthusiasm of the participants. Then, ask each participant to <u>say one thing</u> they will do as a result of this training. Trainers should go first. Start statement with "I commit to…" *(Note to trainer: Depending on the size of the closing circle, this activity can take several minutes. In the case of a large number of participants, it can be helpful to suggest that each woman state one item or even one word that describes her commitment.)* 18. Continue around the circle. 19. While remaining in the circle thank participants for their contributions. Finish closing circle with the closing prayer. ♦ Thank you for your contributions. You all have been a wonderful group. Now let us close with a prayer. _____ is going to lead us.

Breast & Cervical Health
Session 4 Role Plays

- **Jobless Janice**
- **Caring Clara**
- **Thinking Thelma**
- **Anxious Annie**

Jobless Janice

LHA: (Sees a woman from her neighborhood at the post office) "Hi, Janice. I heard you quit work recently. Are you enjoying your free time?"

Janice: " Enjoying? I've spent more time at the doctor's office this past year than ever. That's why I had to quit working. I'm not going to enjoy paying all those doctor bills now that I'm not working. And my doctor just told me to go get a mammogram. How am I going to pay for that now?"

LHA: "It is still important for you to keep that mammogram appointment and I'm glad you plan to go. Since you lost your insurance from your job and you're not old enough for Medicare, there may be some other groups that can help pay for your mammogram. Have you talked to social services to see if you are eligible for benefits under the state Medicaid program? I also know that the health department has federal funds to pay for mammograms for women who don't have health insurance or Medicaid. A call to the health department – *name specific BCCCP coordinator* – might be just what could help you out."

Caring Clara

Clara: "Hi,_____. I'm glad I ran into you today. My Aunt Bessie got a call from her doctor telling her she had to go back for another test because her Pap smear was abnormal. Her appointment isn't until next week and she is worried because she doesn't know what that means, and how much all this might cost. I'm afraid she won't go."

LHA: "I hope you will encourage your Aunt Bessie that she really needs to keep her doctor appointment about her abnormal results. Until she talks to the doctor, she doesn't know what she's dealing with. Does your Aunt know that cervical cancer is treated easily when it is detected early?"

Clara: " I don't think she has much information on cervical cancer. She asked me if I had any of those materials you were giving out at the health fair."

LHA: "I have some in my car that I can give you right now. Also, if your Aunt Bessie is eligible under the income guidelines, there are funds available through the health department to pay for follow-up appointments for abnormal Pap smears. Some women don't want their business known, but if Aunt Bessie would like to talk with me, here is my number. I may be able to give her some information that helps her and I will encourage her to keep that doctor's appointment. She is not alone in this."

Thinking Thelma

LHA: (Introduce yourself to "advisee" and try to figure out STEP for mammography and then Pap smear screening)

Thelma: I'm thinking about getting a mammogram since my doctor told me I should. But she didn't tell me where to go or how much it would cost.

LHA: (Advise based on what Thelma told you and then transition to Pap smear screening)

Thelma: I've had a Pap smear before. It's been a while, though. Actually, I haven't had one since I moved to Williamston five years ago. In New York, I had the best doctor ever. He used to speak to me while he was doing the test so I wouldn't feel so funny. I know I should have a Pap but can't imagine finding anyone as nice as Dr. Stevens.

LHA: (Advise based on what Thelma told you.)

Anxious Annie

LHA: Introduce yourself to “advisee” and try to figure out STEP for mammography and then Pap smear screening

Annie: I know I should get a mammogram but I’m too nervous. They once told my friend that hers was abnormal and she had some other sort of test and everything was fine. I’d hate to go through that.

LHA: Advise based on what Annie told you and then transition to Pap smear screening

Annie: It’s been a while since I had a Pap smear and I would like to change that but I don’t have an ob/gyn anymore. I stopped seeing her when I was done having babies.

LHA: Advise based on what Annie told you

Older Olivia

Olivia: "Hi, _____. My, that is a pretty necklace you have on with that dress."

LHA: "Thank you Olivia. These beads are my breast cancer teaching necklace. Have I ever told you the story behind this necklace?"

Olivia: "No, I don't think so. What is it?"

LHA: "These beads represent the different size at which breast cancer can be detected by different ways. This largest bead is the size of a lump that might be found by a woman who never checks her breasts or never gets her breasts examined by a doctor or nurse. This smallest bead is the size lump that can be found by a mammogram up to 2 years before it can be felt by a woman or her doctor. Early detection of breast cancer can save our lives because early treatments can mean a cure. Have you had your mammogram this year?"

Olivia: "NO, I'm too old for that kind of thing. I'm not having babies and I've been a widow for 18 years. I'm not interested in a mammogram. Besides, I don't have any way to get over to the hospital for that kind of test."

LHA: "You are never too old for a mammogram. It could save your life and give you peace of mind about your health. If getting to your appointment is the only thing holding you back, tell me when it is and I'll see if one of our Save Our Sisters volunteers can't pick you up and take you. Would that be okay with you?"

Lay Health Advisor
Program Institutionalization Guide

Compiled by the North Carolina Breast Cancer Screening Program
For Agency Partners in Eastern North Carolina

Contents

This guide is intended to provide information to potential partners of the North Carolina Breast Cancer Screening Program regarding the continuation and expansion of a valuable health resource in their communities: Lay Health Advisors. Material included in this guide will provide:

- Background information about lay health advisors;
- Assistance with grant-writing to fund lay health advisor groups;
- Ideas for developing and expanding the network of lay health advisors.

Who Are Lay Health Advisors and What Do They Do?

Lay Health Advisors (LHAs) help individuals and groups take greater control over their health and their lives. They promote healthy living by educating about how to prevent disease and injury and by helping community residents understand and access formal health and human service systems. LHAs are able to achieve these results because they have specialized training and share experience, language or culture of the communities they serve.

LHAs work within and as a complement to health care delivery systems. Paid and volunteer LHAs are typically based in community clinics, nonprofit organizations, and public health departments, although increasingly they are also found in for-profit environments. As the diversity of the U.S. population increases, and as the rate of change in health systems accelerates, the opportunity to expand the LHA role grows.

Adapted from The Annie E. Casey Foundation's 1998 publication, A Summary of the National Community Health Advisor Study: Weaving the Future. To obtain a copy of free copy of the guide, call (520) 626-7946.

NC-BCSP uses a lay health advisor model that is based on a concept of "natural helping." Natural helpers are respected community members who others may go to as a "first-contact person" when they have a health or other problem (1). Community members often turn to natural helpers for advice or referrals before or instead of seeking professional help (2).

Natural helpers become lay health advisors through their participation in training such as that offered by NC-BCSP. NC-BCSP lay health advisors receive approximately twelve hours of training to increase their knowledge about breast and cervical cancer and learn counseling techniques. After completing training, LHAs are ready to become leaders for breast and cervical health promotion in communities.

Generally, LHAs improve the health by playing three roles. The first role is to assist individuals they know and meet by providing them with information, emotional support and direct voluntary service. For example, a lay health advisor might tell a friend about the benefits of getting a mammogram or even drive her to a screening appointment. A second role is to help women negotiate with agencies for services. To achieve this, a group of LHAs might form a partnership with a local health agency and help the agency tailor its services for women who are unfamiliar with its operations. A third LHA role is community organizing (2-3). LHAs, as a group, might

develop an "Mother's Day initiative" to distribute information about mammography at local churches. The goal of all three roles is increase community participation in healthy decision-making.

Breast cancer is the health problem that LHA interventions are used most frequently to address. However, the role of LHAs is expanding. Across the country, they are also turning their attention other types of cancer, domestic violence, diabetes, lead, hypertension and prenatal issues.

1. Salber, E.J. Where does primary care begin? The health facilitator as a central figure in primary care. *Israeli Journal of Medical Science* 1981; 17:100-111.
2. Eng, E., & Smith, J. Natural helping functions of lay health advisors in breast cancer education. *Breast Cancer Research and Treatment* 1995; 35:23-29.
3. Eng, E., & Young, R. Lay health advisors as community change agents. *Family and Community Health,* 1992; 15:24-40.

When talking to women being recruited or trained for NC-BCSP's lay health advisor program, we offer the following description of an LHA:

Lay: comes from the word "laity" which means not ordained. This word is commonly used to refer to church members who are leaders but not ordained – such as lay ministers. It is also used to describe anyone who works in an area, such as health, who is not a professional. Our LHAs are not professional health care providers.

Health: Health is defined by the World Health Organization as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity." We think of health as a state of being – a quality of life.

Advisor: An advisor is a person who provides recommendations and information so individuals can make informed decisions. A person who is seen by others in the community as a "natural helper," someone that others go to for guidance. An advisor serves as a bridge between women in the community and information they need to be healthy.

The role of lay health advisors in our program is to be an informed, responsive community members. We're do not ask you to try to take the place of a doctor or a nurse. Your responsibility is to help women stay healthy by advising them, within the scope of your training – serving as a bridge – to help them understand the importance of breast & cervical health and the need to get regular screening tests (mammograms and Pap smears).

LHAs use any opportunity at their disposal to inform and educate community members. They may:

- Advise women one-on-one (in person and on the telephone)
- Wear beaded necklaces, t-shirts and pins
- Talk to women in churches and at work
- Plan new activities with the LHA group
- Give presentations at churches, nursing homes, women's groups
- Set up a booth at local events like health fairs or county fairs
- March in parades
- Pass out information at busy places like the post office or church
- Attend LHA group meetings
- Talk routinely to the their Community Outreach Specialist about what they're doing

As you can see from the list of activities, each LHA works very hard to protect the health of the women she knows and cares about. Some of these activities are individual things – like advising women one-on-one; some of these activities are group things – like marching in parades. There is room for each woman, each LHA, to participate at a level that's comfortable and matches her personality. And when are think about all of us working together, it's really quite powerful. All of us working together as a group to promote breast and cervical health can reach a lot of women and really make a big difference.

While we don't expect you to be involved in all of the activities on this long list, there are some that we do expect of you as an LHA for the BCSP. All LHAs are expected to:

- Advise female friends, family members, and close associates about mammography
- Present herself as a resource so people can come to her and ask questions (wear the beads from time to time, let others know she is an LHA)
- Attend regular LHA meetings
- Keep her COS informed about what she has been doing, so LHA efforts can be reported back to funding sources.

Many LHAs have found that they can work breast and cervical health promotion into the things they are already doing, like talking to their women's club meeting, church circle, sorority meeting, for example.

Why Use A Lay Health Advisor Model?

Lay Health Advisors have shown remarkable effectiveness in linking individuals with the health care system, with insurance coverage, and with sources of continuous, appropriate medical care. Benefits of these activities include:

- Reduction of emergency room visits, hospital visits, length of time in a hospital, and the number of complications for certain illnesses.
- Greater availability of cost-effective, culturally competent home and clinically-based services compared with other services which may be unavailable or cost more.
- More focus on individual needs associated with health care delivery such as help obtaining non-medical services that reduce barriers to medical care for some people.
- Greater trust between client and the health care delivery system that promotes improved timely use of medical services and better compliance with medical care providers' treatment instructions.

In many programs, LHAs not only identify and link people needing health or support services, they also coordinate clients' relationships with multiple service systems. For clients who need extra social or logistical support to maintain their efforts toward defined goals, LHAs can be a valuable and cost-effective way to maintain connection with clients who are at the highest risk of dropping out of a complicated system.

Adapted from The Annie E. Casey Foundation's 1998 publication, A summary of the National Community Health Advisor Study: Weaving the Future. To obtain a free copy of the guide, call (520) 626-7946.

Social network interventions using lay health advisors have demonstrated that knowledgeable, trusted members of a community can be effectively trained to promote mammography and cervical exams among marginalized populations, including African American (1-6), Vietnamese American (7), Native Hawaiian (8), Native American (9, 10) and Hispanic women (11, 12). Theoretically, positive changes in screening behavior in target populations are derived through the direct contact that a lay health advisor has with her friends and acquaintances and, even more importantly, through "diffusion of innovation" that takes place in a tightly bound community

with shared norms. Diffusion of innovation theory posits that information travels more rapidly through peer networks than through more hierarchic information dispersal structures (13).

Social Support: Social support, including emotional (trust, concern, empathy), instrumental (tangible help offered as transportation services and cost reductions), informational (advice, instruction, suggestion) and appraisal (affirmation, feedback) support (15-17) is linked positively to mammography initiation and use (18-20), particularly among underserved populations (5, 21-25). Women who receive support from a friend are more likely than those who do not to have a mammogram at some point in their lives, as well as to have had one recently (26). Instrumental support (e.g. transportation or information about programs to pay for mammograms) from a friend, colleague or family member is an important enabling factor that operates through a woman's social network. Furthermore, women who have had a mammogram report higher levels of social support from close relationships than those who have never had one (27).

Social influence: Social influence (sometimes referred to as subjective norms or perceived network or community norms) encompasses both women's perceptions of attitudes held by social network members towards a behavior (in this case mammography screening) and the impact these perceptions have on women's behavior. While effects of social influence are less easily calculated than effects of social support (individuals' perceptions of community norms can be erroneous (28)), higher screening rates are found among women who perceive mammography as a common practice among peers (18, 29). Social influence appears to be a factor for who gets, or intends to get, a mammogram (30-32). Living among friends and family who support mammography is conducive to engaging in mammography use, but social context alone is insufficient. An equally important factor is a woman's motivation to comply with the wishes and perceived norms held by people who matter most to her. For some women, influential others may be friends or health care providers; for others, family members may be more influential in encouraging mammography.

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An Overview of the North Carolina Breast Cancer Screening Program

Mission

The North Carolina Breast Cancer Screening Program's (NC-BCSP) mission is to reduce late-stage diagnosis of breast and cervical cancer in older African American women. The program is based at UNC Lineberger Comprehensive Cancer Center in Chapel Hill and serves women living in 5 eastern North Carolina counties.

The key to cancer survival is early diagnosis and treatment. African American women have higher cancer mortality rates than white women, in large part, because of later stage at diagnosis. This is true for both breast and cervical cancer. Regular mammograms can detect breast cancer early and reduce deaths by 30% for women 50 years and older. Pap tests every 1-2 years can virtually eliminate deaths from cervical cancer. Despite the availability and effectiveness of these two tests, African American women, especially older, rural women, have low screening rates.

NC-BCSP works to increase mammography and Pap testing rates and to improve quality and length of life for rural African American women. These efforts will contribute to equality in health between African American and white women.

Specific Aims

NC-BCSP was launched as an eight-year project (1992-2000) to promote mammography use by older African American women in five counties: Beaufort, Bertie, Martin, Tyrrell and Washington. In the first eight years, NC-BCSP achieved its objective of increasing mammography use by African American women ages 50 years and older. The project's success has provided a strong foundation to develop and test new initiatives to improve the health of older, rural African American women. Specific aims for 2000-2003 are to:

- **Expand the population focus to include African American women 40 years and older.** From 1992-2000, NC-BCSP focused on women 50 years and older for mammography, as recommended by the National Cancer Institute (NCI). Today, NCI and the American Cancer Society endorse mammography every 1-2 years for women ages 40 and older.

- **Increase initial use of screening mammography by women who have never had a mammogram.** Initiation of mammography by all women is imperative to closing the screening gap between black and white women. After 8 years of NC-BCSP intervention, despite movement in a positive direction, black women remain more than twice as likely as white women to report they had never had a mammogram (19.3% versus 9.7%).

- **Increase repeat mammography screening by African American women.** Despite a national increase in mammography use by women 50 and older (from 27% in 1987 to 74% in 1997), maintaining the recommended screening schedule is low for African American women. Only 64% of African American women in NC-BCSP counties followed the recommended screening schedule (2 or more mammograms in the past 5 years) as compared to 78% of white women.

- **Increase the Pap testing rate among African American women ages 40 and older.** NC-BCSP has expanded its mission to address the problem of late-stage diagnosis of cervical cancer in African American women. North Carolina Cancer Registry shows that in NC-BCSP counties African American women are more likely than white women to be diagnosed with late-stage cervical cancer (63% vs. 43%). Knowing that early treatment can prevent death from cervical cancer is one way to strengthen African American women's sense of self-determination and personal control over their lives and their bodies.

In addition, NC-BCSP has a number of secondary objectives to:

- improve women's knowledge of, attitude toward and intention to obtain screening mammograms and Pap tests;
- investigate the relationship between cancer anxiety and specific screening tests (mammography and Pap);
- improve providers' skills in counseling women for mammography;
- determine which aspects of NC-BCSP interventions are most effective for increasing mammography use, and;
- promote the dissemination of effective interventions.

Research Strategies
NC-BCSP uses three complementary and mutually reinforcing strategies. The **Outreach** strategy uses a lay health advisor network of approximately 140 natural helpers. The lay health advisors (LHAs) are all older African American women. They are trained to promote Pap testing and mammography among their friends, family, co-workers and other women.

Inreach and **Access** strategies aim to assure that the supply of high-quality, affordable mammography and Pap testing services are available to meet increased demand stimulated by LHAs' and other public health efforts. **InReach** develops and disseminates training programs for radiologic technologists, primary care physicians, nurse practitioners and physician assistants. **Access** addresses barriers to mammography and Pap testing, which include cost, transportation and inconsistent referral patterns. **Access** helps agencies formalize procedures and information on referral for routine mammography and follow up for abnormal test results.

NC-BCSP uses two approaches to measure its effectiveness. The primary **outcome evaluation** consists of a community trial with a quasi-experimental, pre-post-test design to compare changes in women's self-reported mammography use, attitudes and intentions between the five-county intervention and a similar five-county comparison area. Staff also conduct **process evaluation** activities to monitor immediate changes at the individual, practice and agency levels.

Support
NC-BCSP receives funding support from:

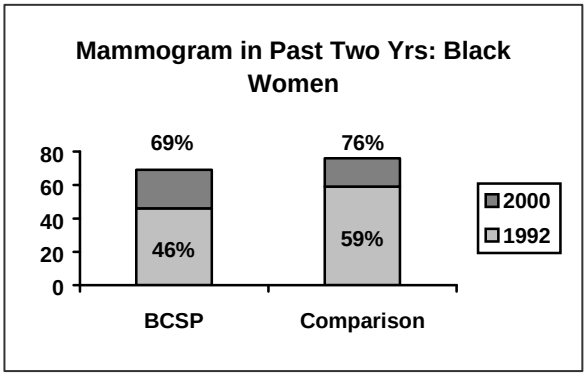
- National Cancer Institute
- Susan G. Komen Breast Cancer Foundation
- Avon Breast Health Access Fund

- Kate B. Reynolds Charitable Trust
- The Pittsburgh Foundation
- American Cancer Society
- Triangle Affiliate of the Susan G. Komen Foundation

NC-BCSP is also the beneficiary of extensive in-kind support from local health agencies, churches and community organizations that donate meeting space, office space, supplies and support for lay health advisor training, community events and the NC-BCSP Community Advisory Group. The success of NC-BCSP is due, in large part, to the support of many collaborators who share our commitment to improve health and quality of life for older, rural African American women.

NC-BCSP Lay Health Advisors in Beaufort, Bertie and Martin Counties

NC-BCSP recently completed an 8-year community trial (1992-2000), funded by the National Cancer Institute, to assess our intervention's effectiveness for increasing screening rates. A cohort of 2000 women (1000 Black, 1000 White) was recruited from the 5 intervention counties and 5 neighboring comparison counties. Participants completed a series of three interviews (1993-94, 1996, 1999-2000) to determine changes in self-reported mammography use. Study results show that, overall, Black women in the intervention counties experienced a significantly greater increase in mammography rates compared to Black women in NC-BCSP's comparison counties. NC-BCSP lay health advisors have helped boost mammography use by older African American women. From 1992-2000, mammography use by Black women increased 23 points (46% to 69%) in our intervention counties, overall, as measured by the program evaluation.

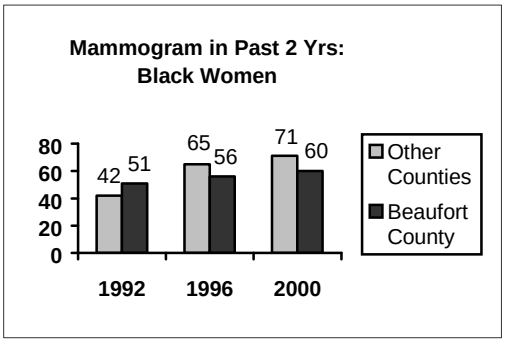


Improvements were dramatic among women with annual household incomes below $12,000 and and women with less than an 8th grade education. Among low-income women, racial differences in mammography use virtually disappeared.

Beaufort

Beaufort County has approximately 25 active LHAs coordinated by two part-time Community Outreach Specialists, Mary Gurley in Washington and Brenda Harris in Belhaven. The LHAs are based in Belhaven, Washington, Aurora and Chocowinity.

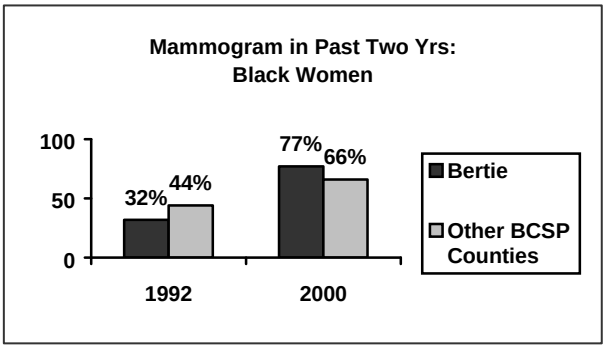
NC-BCSP's county-level data show that not all counties made equal strides. As illustrated in the diagram to the right, at baseline (1992), interviews showed that 51% of Black women in Beaufort County reported a mammogram in the past two years, compared to only 42% of Black women in the other four intervention counties (Bertie, Martin, Tyrrell and Washington). Over the next 8 years, however, Beaufort County women lost their lead. By 2000, 71% of Black women in the other intervention counties reported a recent mammogram compared to only 60% in Beaufort County. Over eight years, recent mammography use by Black women increased only 9 percentage points in Beaufort County compared to 29 percentage points in the other intervention counties.



Bertie County

Bertie County has 45 active LHAs based in the communities of Merry Hill, Windsor, Powellsville, Colerain, and Kelford. Bertie County LHAs are coordinated by two part-time

Community Outreach Specialists, Lucille Bazemore and Survilla Cherry, each working approximately 10 hours per week.

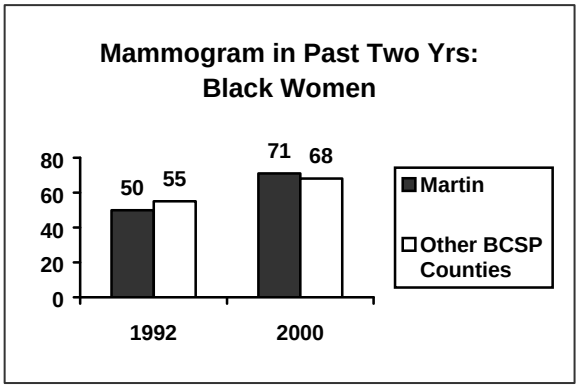


Over the eight-year study period, Bertie had the greatest gains in screening rates. Just prior to the program, mammography use by older African American women was lower in Bertie than in the other 4 intervention counties. By the end of the study, the mammography use rate in Bertie had more than doubled. It increased 43 percentage points, from 32% to 75%; a 130% increase, an increase well above that of the other 4 counties that had NC-BCSP programs. Black women in Bertie have already exceeded the Healthy People 2010 goal of 70% of African American women reporting a mammogram in the past 2 years.

Martin County

Martin County has approximately 65 active LHAs based in the communities of Williamston, Robersonville, Parmele, Oak City, Jamesville, Hamilton, Plymouth, Hassell, Creswell and Columbia. Eva Hill is the Community Outreach Specialist coordinating this group of LHAs. Ms. Hill is employed full-time and also coordinates LHA activities in Tyrrell and Washington Counties.

Like Bertie, Martin has an important story to tell. Just prior to our program, mammography use by older African American women was lower in Martin than in the other 4 intervention counties. By the end of the study, the mammography use rate in Martin had increased from 50% to 71%; a 40% increase.



NC-BCSP's Training Curriculum for Lay Health Advisors

NC-BCSP recently developed an LHA educational curriculum. It reflects nine years of NC-BCSP experience in developing and testing lay health advisor interventions in eastern North Carolina and a wealth of skill and knowledge from experts both inside and outside of NC-BCSP. The twelve-hour training program is presented in four sessions:

Session 1: Background
- History of NC-BCSP
- What is an LHA
- Breast and Cervical Health: Statistics
- Risk Factors and Signs/Symptoms

Session 2: Screening for Early Detection
- Female Breast and Reproductive Anatomy
- Early Detection: Mammography and Pap Smears
- Barriers to Mammography and Pap Screening
- Role Plays

Session 3: Advising Skills
- Behavior Change is a Process of Stages
- Identifying Women by their Readiness to Have a Mammogram and/or Pap Test
- Helping Women to Value the "Pros" of Mammography and/or Pap Testing
- Role Plays

Session 4: Community Resources
- Types of Health Care Providers
- How to Obtain a Referral
- Financial and Transportation Resources
- Role Plays
- Support Services Following an Abnormal Result or Cancer Diagnosis
- Testimony from Cancer Survivors

Graduates of the training are knowledgeable and skilled in advising and assisting women to have both mammograms and Pap tests for early cancer detection. Most LHA programs are disease-specific, targeting a single health problem. One of the unique qualities of NC-BCSP's updated curriculum is its integrated focus on two types of cancer, leading LHAs to take a more holistic approach to women's health promotion.

The third session, which focuses on advising skills, breaks new ground in LHA training. It draws on the Stages of Change theory to teach LHAs effective techniques for persuading women to have mammograms and Pap tests. Using this theory, LHAs learn why and how to tailor their message according to each woman's level of resistance or readiness to engage in breast and

cervical cancer screening. To our knowledge, this is the first time that Stages of Change theory has been applied to the design and actual implementation of an LHA program.

This well-established theory proposes that behavior change is a gradual process that occurs in stages. Thus, counseling women in a manner that is matched to their stage is more effective than a generic counseling approach. Individuals are more or less receptive to and persuaded by different types of messages depending on their "stage of change" regarding a specified health behavior. For example, a woman who is *not* considering mammography is not likely to be receptive to messages that simply implore her to have a mammogram or deliver information about how to get a mammogram. Instead, she is more likely to be influenced by information about the benefits of mammography (i.e. peace of mind, finding cancer early when it is easiest to treat, etc.) A woman *considering* getting a mammogram, but who hasn't yet done so, needs support and personalized suggestions for overcoming her barriers. Finally, a woman who has mammograms on schedule needs praise and encouragement to help her stay on track.

The highly participatory curriculum also takes into account a range of learning styles and pays particular attention to the needs of older learners. Activities are designed so that older lay health advisors, many of whom had physical limitations, can participate fully. We also ensure that the curriculum allows LHAs to express and celebrate their strong commitment to spirituality; each session opens and closes with a prayer that addresses some aspect of the training content. Also, some of the incentives and health promotion materials developed for the training have spiritual messages consistent with NC-BCSP's mission of health promotion. For example, a flashlight given at the end of Session 3 reinforces the notion of LHAs "lighting the way" for women not yet getting screened.

The training guide is fully documented with detailed instructions to trainers including materials lists and a suggested script to accompany each lesson. Any skilled trainer or health care provider should be able to deliver the 12-hour training using our manual, handouts, and exercises as a guide.

Useful Statistics

Breast cancer is

- the most common form of cancer
- second leading cause of death for US women
- more than half of breast cancer cases occur in women older than 65
- in 1999, an estimated 175,000 new cases of the disease were diagnosed in NC, while 43,700 women died
- in North Carolina only 39% of women age 65 and older had a mammogram in 1999 (Medicare Part B claims data)

Cervical Cancer is

Black women are 2.5 times more likely than white women to die of cervical cancer (age adjusted rates: 6.1/100,000 v. 2.5/100,000 respectively

Colorectal cancer is

- the second leading cancer killer in America, killing more people than either breast or prostate cancers
- in 1996, CRC was the leading cancer-cause of hospitalization in the United States
- everyone over the age of 50 is at risk for CRC and should have CRC screening
- if caught early with screening, CRC is one of the more easily treatable cancers
- Medicare provides coverage for each of the different CRC screening tests in North Carolina 2,626 Medicare consumers were hospitalized for CRC in 1998

Year 2000 US Census

	% Black	**% Poverty**	**Pop. Density**
Beaufort	31.6	19.2	51.1
Bertie	61.6	24.4	29.2
Martin	45.1	25.5	54.2
Tyrrell	40.3	20.7	9.9
Washington	45.1	19.7	40.2
Average	**44.9**	**21.9**	**36.9**
Avg-NC	**22.2**	**13.0**	**136.1**

Print census relevant pages for 3 books plus a copy for us.

LHA Career Development Themes

The following themes have emerged from discussion groups with LHAs from around the country.

LHA commitment is significant, and community change is an important reward of LHA work. LHAs, both paid and volunteer, expressed a high commitment to their communities. LHAs spoke of the 24-hour commitment that was required when serving as an LHA. LHAs spoke of a sense of belonging in their communities that kept them motivated. Some LHAs expressed concern that professionalization of the field may negatively effect their roles in communities, allying them more with the health care system than with their communities.

The LHA role is demanding and without boundaries. One of the strongest messages from discussion groups was that the LHA role is demanding and lacks clear boundaries. There are several aspects to this lack of boundaries.

Many things are expected that are not in the job description. LHAs are sometimes asked by both medical professionals and by community members to do more than they feel prepared for. LHAs spoke of expectations from fellow community members that extended far beyond their own perceived sense of their role. Often the limits to a LHA's role is not clearly defined

LHAs' own personal boundaries are sometimes threatened, and LHAs at times are in danger. Several LHAs spoke of being in dangerous situations. LHAs are often in remote areas or conflict-ridden city neighborhoods. LHAs can be exposed to wild dogs, street violence and domestic violence during home visits. To reduce such risks, some LHAs work in pairs or carry portable telephones to stay in contact.

Community members and LHAs are not separated by clear boundaries. LHAs take their work home. "Our job is not just in the clinics." People may knock on the door of a neighborhood LHA at any hour. LHAs and LHA supervisors mentioned difficulties posed by LHAs facing challenges similar to their clients. Such blurred boundaries contribute to tension on the job.

The importance of crossing boundaries. On the positive side of fluid boundaries, LHAs spoke of being able to cross agency boundaries as needed and to work with staff in multiple settings. This could be a valuable asset in a fragmented health care system. LHAs also spoke of access to a wide referral network, which allows them to better serve their communities.

Adapted from The Annie E. Casey Foundation's 1998 publication, A Summary of the National Community Health Advisor Study: Weaving the Future. To obtain a copy of free copy of the guide, call (520) 626-7946.