ROSE

Robeson County
Outreach
Screening &
Education Project

Community Health Education Manual

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Robeson Health Care Corporation
Wake Forest University School of Medicine

HEALTH EDUCATION MANUAL

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CHAPTER 1

General Information

1.1 Use of This Manual

This manual contains information and instructions necessary to complete assignments for the **R**obeson County **O**utreach, **S**creening and **E**ducation **(ROSE)** Project. It is to be used as a training aid and as a reference document throughout this data collection and study intervention period. Included is general information about the study; terms and definitions with which you must be familiar; descriptions of the procedures for making household contacts and interviews and home visits with the sample members; the questionnaire, question-by-question specifications; and administrative procedures.

1.2 About the ROSE Project

ROSE is an important project that is developing and evaluating a program designed to increase early detection of breast cancer by increasing the proportion of low income rural women age 40 and older who receive clinical breast exams and mammograms at appropriate intervals and return for follow-up care (See Appendix A).

The **R**obeson County **O**utreach, **S**creening and **E**ducation **(ROSE)** Project is a four year project funded by the National Cancer Institute of the National Institutes of Health. It is being conducted by researchers from the Wake Forest University School of Medicine and Robeson Health Care Corporation (RHCC). This project will be conducted in Robeson County, NC. This county has a population comprised of three principal ethnic groups of approximately equal size: whites, African Americans and Native Americans. An individualized health education program will be developed and compared to a brochure plus physician letter in a randomized trial design among 1000 women aged 40 and older who are patients of Robeson Health Care Corporation, the principal provider of health care for this population. RHCC consists of four clinics. They are Lumberton Health Center, Maxton Medical Services, Julian T. Pierce

Health Center and South Robeson Medical Clinic. An additional aim of the project relates to assuring adequate follow-up among women with abnormal tests results.

Specific aims of the project are:

* to identify barriers to obtaining regular clinical breast exams and mammograms,
* to develop a health education program to improve knowledge and practices, with regards to breast cancer screening,
* to address the identified structural and personal barriers to behavior change and
* to motivate women in the target population to obtain clinical breast exams and mammograms.

We will also evaluate, through use of a randomized design, the impact of the health education program compared to a brochure plus physician letter on the proportion of women obtaining regular clinical breast exams and mammography. The project will explore the differential effects of the health education intervention to enhance participation in breast cancer screening among rural white, African American and Native American women, groups that are traditionally underserved by cancer control efforts and services. Factors will be identified that impede follow-up and treatment of abnormal or suspicious findings with a goal of improving adherence with recommendations for follow-up of abnormalities detected among women in the study.

Data will be collected by in person interview with verification of mammography and CBE by medical record review by RHCC staff. A total of 1000 women will be recruited and randomized into either the intervention group or the brochure group. Follow-up will be staggered over a 1 year period for each participant.

If this program is successful in improving breast cancer screening practices among this population of tri-racial women, community health educators from a variety of community organizations can be trained and supervised by health departments to deliver similar programs to rural women.

The ultimate goals of **ROSE** are to improve knowledge and attitudes about cancer screening among rural and minority women and to increase the use of early detection procedures in these women. Other goals of the project are to

identify barriers to early cancer detection in the target population and to assess compliance to follow-up recommendations for abnormal findings.

ROSE hopes to benefit the target population by increasing awareness of breast cancer and its related problems and by teaching the importance of screening for early detection and prevention. The ultimate future benefit for everyone will be lower death rates from cancer among low income minority women in the community.

* **Who Can Participate?**

Eligible participants will include women, age 40 and older who are patients of Robeson Health Care Corporation and reside in Robeson County. All participants will receive their usual medical care from RHCC.

* **What Has Happened?**

During the first 6 months of the project the first phase of the project concentrated on community analysis to identify elements of the target population, the community and health care systems that will influente the intervention. Four focus groups were conducted to collect impressions about clinical breast exams, mammograms and follow-up care, educational materials and barriers to behavior change. This will help refine identified concepts that will provide the foundation of the educational program.

Two types of advisory committees were formed for the project. The Medical Advisory Committee consist of medical professionals from the area. A community advisory group consisting of women from the target population were also recruited. Each group will meet quarterly with project staff to provide reactions to project issues including community relations and appropriateness of educational materials to be used in the homes of women in Robeson County.

* **What Is Happening?**

The project is currently in the field pretesting and staff training phase. The pretesting will focus on appropriateness of language and

illustrations in the educational materials, estimates of time required for implementation and identifying unanticipated barriers. A Medical Advisory Board and a Community Advisory Board has been formed. They consist of local medical and community leaders, and will advise the project staff on all aspects of the study. (See Appendix B)

1.3 Organizational Structure

ROSE is funded by the National Cancer Institute (NCI), one of the National Institutes of Health. **Dr. Electra Paskett** of Wake Forest University School of Medicine is the Principal Investigator and **Dr. Dennis Stuart** of Robeson Health Care Corporation is a Co-Investigator (See Appendix C).

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CHAPTER 2

About The Breast

2.1 The Normal Breast: Breast Growth and Development

Breasts, like all body organs, are affected by normal life changes. The breasts are primarily under the influence of ovarian hormones during puberty, pregnancy, breast-feeding, each menstrual cycle, and at menopause. In a woman of childbearing age, the glandular tissue predominates. As a woman ages, fatty tissue replaces much of the glandular tissue.

Breast texture varies not only from woman to woman, but also in the same woman from week to week and over the years. The size and shape of the breasts depend upon heredity and body weight, and they do not necessarily match each other.

Awareness of changes that normally occur will help a woman recognize any abnormal changes, thickening, or lumps that might be found during a monthly breast self-examination.

2.2 Life Style Breast Changes

2.2.1 Puberty

Growth of the breasts begins before the onset of menstruation and it is controlled by female hormones.

2.2.2 Menstrual Cycle

Under the influence of the female hormones, estrogen and progesterone, breasts swell with fluid, most notably during the week before menstruation. Lumps that are tender may appear during this time and should decrease or disappear in the week following the menstrual period -- the best time to examine your breasts.

2.2.3 Pregnancy

Breast changes, including tenderness, occur very early and continue throughout pregnancy. Mammary glands and ducts enlarge, making the breast about one third larger. The breast generally resumes its former size and shape once breast-feeding stops. There is no evidence at this time that prolonged breast-feeding offers any protection against cancer.

2.2.4 Menopause

Mammary glands and ducts begin to decrease in size with the onset of menopause. Supporting fibrous tissue usually thins and slackens, and the breasts may become less firm, and may sag with age.

2.2.5 Weight Changes

Because breasts contain fatty tissue, they increase or decrease in size as your weight changes.

2.3 Breast Lumps

Any noticeable change, thickening, or localized swelling in a woman's breast that wasn't there before may be a lump. Most breast lumps are benign (noncancerous), and most women will experience a benign lump sometime in their lives. The following are common benign breast problems that appear as lumps. (See page four for more anatomical detail.)

2.3.1 Fibrocystic "Disease" is the most common cause of breast lumps in women age 35 to 50, and is responsible for 80% of all breast operations performed. This condition, which is not an actual disease, is probably caused by the mammary glands, ducts, and fibrous tissue overreacting to normal hormonal changes. As a result, multiple pockets of fluid (called sacs or cysts) develop, and an increase in fibrous tissue may form. In some instances, a lump may consist only of fibrous, rubbery tissue (a condition called **mammary dysplasia).** Tenderness and lump size commonly increase during the week

before menstruation and decrease a week after. Fibrocystic disease usually disappears after menopause.

2.3.2 Simple Cysts, a variety of fibrocystic disease, are either single or multiple fluid-filled sacs. With simple cysts, there is no significant increase in fibrous tissue. Tenderness and lump size often fluctuate with the menstrual cycle.

2.3.3 Fibroadenoma, a single solid tumor, is composed of fibrous and glandular tissue. It occurs most frequently in women between 18 and 35, and is usually moveable when felt. Although it is not usually tender, premenstrual tenderness can occur. Nearly all breast tumors in women under age 25 are fibroadenomas.

2.3.4 Papillomas are small, wart-like growths in the lining of a mammary duct near the nipple, which can produce a clear or bloody discharge from the nipple.

2.3.5 Intraductal Papilloma, a small, wartlike growth that projects into breast ducts near the nipple. Any slight bump or bruise in the area of the nipple can cause the papiloma to bleed. Single (solitary) intraductal papillomas usually affect women nearing menopause. If the discharge becomes bothersome, the disease duct can be removed surgically without damaging the appearance of the breast. Multiple intraductal papilomas, in contrast, are more common in younger women. They often occur in both breasts and are more likely to be associated with a lump than with nipple discharge. Multiple intraductal papillomas, or any papillomas associated with a lump, need to be removed.

2.4 Malignant Lumps or Cancerous Lumps

Malignant lumps are usually single, hard, and painless. They develop most often from mammary ducts or glands, and are most commonly found in the upper, outer portion of the breast. Unlike benign lumps, cancerous lumps continue to grow in an uncontrolled manner, and in time will spread beyond the breast. The risk of developing breast cancer increases if you've had breast cancer before, if you have a family history of the disease, or if you've

had a previous biopsy indicating a precancerous condition. In general, the risk of breast cancer rises with age, and is higher if you give birth for the first time after age 30 or if you never give birth. Breast cancer is decidedly a woman's disease -- less than one percent of all breast cancers occur in males. Many authorities think that reducing fat intake can help reduce the chances of breast cancer.

2.4.1 Early Breast Cancer is a small tumor less than an inch in size, located in the breast only. It's important to realize that even an "early" cancer may have been growing for several years before becoming large enough to be felt. Women who examine their breasts each month, visit their doctor for periodic breast examinations, and have periodic mammography are most likely to detect an early breast cancer. Each year in the United States, 150,900 women are diagnosed as having breast cancer. Early diagnosis and proper treatment give these women a better chance of being alive and well in the future.

2.4.2 Advanced Breast Cancer is a larger tumor that has spread from the breast to the lymph nodes. Once this occurs, the chance for cure is reduced, even with surgical removal of the breast and lymph nodes. Of the 44,000 American women who die each year from breast cancer, many could have been diagnosed and treated earlier with regular examinations.

2.4.3 Metastasized Breast Cancer means that cancer cells may have spread not only to the lymph nodes but to other areas of the body as well, commonly the bones, lungs, and liver. Cancer cells usually spread through the lymph system and bloodstream. Unfortunately, the cure rate is low.

2.5 If You Find a Lump

If a woman discovers a lump in one breast, she should check the other breast. If both breasts feel the same, the lumpiness is probably normal. The woman should, however, mention it to her doctor at her next visit.

But if the lump is something new or unusual and does not go away after her next menstrual period, it is time for the woman to call her doctor. The same is true if she discovers a discharge from the nipple or skin changes such as dimpling or puckering. If you do not have a doctor, your local medical society may be able to help you find one in your area.

The woman should not let fear delay her. It is natural to be concerned if one finds a lump in her breast. But remember that 8 out of 10 of all breast lumps are not cancer. The sooner any problem is diagnosed, the sooner it can be treated, thus, increasing the chances of survival. Finding breast cancer early is the most important factor in the fight against breast cancer.

2.5.1 Clinical Evaluation

No matter how the breast lump was discovered, the doctor will want to begin with a medical history. What symptoms has the woman had and how long has she had them? What is her age, menstrual status, general health? Is she pregnant? Is she taking any medications? How many children does she have? Does the woman have any relatives with benign breast conditions or breast cancer? Has the woman previously been diagnosed with benign breast changes?

The doctor will then carefully examine the woman's breasts and will probably schedule her for a diagnostic mammogram, to obtain as much information as possible about the changes in her breast. This may be either a lump that can be felt or an abnormality discovered on a screening mammogram. Diagnostic mammography may include additional views or use special techniques to magnify a suspicious area or to eliminate shadows produced by overlapping layers of normal breast tissue. The doctor will want to compare the diagnostic mammograms with any previous mammograms. If the lump appears to be a cyst, your doctor may ask you to have a sonogram (ultrasound study).

2.5.2 Aspirating a Cyst

When a cyst is suspected, your doctor may proceed directly with aspiration. This procedure, which uses a very thin needle and a syringe, takes only a few minutes and can be done in the doctor's office. The procedure usually is not very uncomfortable, since most of the nerves in the breast are in the skin.

Holding the lump steady, the doctor inserts the needle and attempts to draw out any fluid. If the lump is indeed a cyst, removing the fluid will cause the cyst to collapse and the lump to disappear. Unless the

cyst reappears in the next week or two, no other treatment is needed. If the cyst reappears at a later date, it can simply be drained again.

If the lump turns out to be solid, it may be possible to use the needle to withdraw a clump of cells, which can then be sent to a laboratory for further testing. (Cysts are so rarely associated with cancer that the fluid removed from a cyst is not usually tested unless it is bloody or the woman is older than 55 years of age.)

2.5.3 Biopsy

The only certain way to learn whether a breast lump or mammographic abnormality is cancerous is by having a biopsy, a procedure in which tissue is removed by a surgeon or other specialist and examined under a microscope by a **pathologist.** A pathologist is a doctor who specializes in identifying tissue changes that are characteristic of disease including cancer.

Tissue sample for biopsy can be obtained by either surgery or needle. The doctor's choice of biopsy technique depends on such things as the nature and location of the lump, as well as the woman's general health.
Surgical biopsie scan be either excisional or incisional. An **excisional biopsy** removes the entire lump or suspicious area. Excisional biopsy is currently the standard procedures for lumps that are smaller than an inch or so in diameter. In effect, it is similar to a **lumpectomy,** surgery to remove the lump and a margin of surrounding tissue. Lumpectomy is usually used in combination with radiation therapy as the basic treatment for early breast cancer.

An excisional biopsy is typically performed in the outpatient department of a hospital. A local anesthetic is injected into the woman's breast. Sometimes she is given a tranquilizer before the procedure. The surgeon makes an incision along the contour of the breast and removes the lump along with a small margin of normal tissue. Because no skin is removed, the biopsy scar is usually small. The procedure typically takes less than an hour. After spending an hour or two in the recovery room, the woman goes home the same day.

An **incisional biopsy** removes only a portion of the tumor (by slicing into it) for the pathologist to examine. Incisional biopsies are generally reserved for tumors that are larger. They too are usually performed under local anesthesia, with the woman going home the same day.

Whether or not a surgical biopsy will change the shape of your breast depends partly on the size of the lump and where it is located in the breast, as well as how much of a margin of healthy tissue the surgeon decides to remove. You should talk with your doctor beforehand, so you understand just how extensive the surgery will be and what the cosmetic result will be.

Needle biopsies can be performed with either a very fine needle or a cutting needle large enough to remove a small nugget of tissue.

- **Fine needle aspiration** uses a very thin needle and syringe to remove either fluid from a cyst or clusters of cells from a solid mass. Accurate fine needle aspiration biopsy of a solid mass takes great skill, gained through experience with numerous cases.
- **Core needle biopsy** uses a somewhat larger needle with a special cutting edge. The needle is inserted, under local anesthesia, through a small incision in the skin, and a small core of tissue is removed. This technique may not work well for lumps that are very hard or very small. Core needle biopsy may cause some bruising but rarely leaves an external scar, and the procedure is over in a matter of minutes.

At some institutions with extensive experience, aspiration biopsy is considered as reliable as surgical biopsy; it is trusted to confirm the **malignancy** of a clinically suspicious mass or to confirm a diagnosis that a lump is not cancerous. Should the needle biopsy results be uncertain, the diagnosis is pursued with a surgical biopsy. Some doctor prefer to verify all aspiration biopsy results with a surgical biopsy before proceeding with treatment.

Localization biopsy (also known as needle localization) is a procedure that uses mammography to locate and a needle to biopsy breast abnormalities that can be seen on a mammogram but cannot be felt (nonpalpable abnormalities). Localization can be used with surgical biopsy, fine needle aspiration, or core needle biopsy.

For a surgical biopsy, the radiologist locates the abnormality on a mammogram (or a sonogram) just prior to surgery. Using the mammogram as a guide, the radiologist inserts a fine needle or wire so the tip rests in the suspicious area -- typically, an area of micro calcifications. The needle is anchored with a gauze bandage, and a second mammogram is taken to confirm that the needle is on target.

The woman, along with her mammograms, goes to the operating room, where the surgeon locates and cuts out the needle-targeted area. The more precisely the needle is placed, the less tissue needs to be removed.

Sometimes the surgeon will be able to feel the lump during surgery. In other cases, especially where the mammogram showed only micro calcifications, the abnormality can be neither seen nor felt. To make sure the surgical specimen in fact contains the abnormality, it is x-rayed on the spot. If this **specimen x-ray** fails to show the mass or the calcifications, the surgeon is able to remove additional tissue.

Stereotactic localization biopsy is a newer approach that relies on a three-dimensional x-ray to guide the needle biopsy of a nonpalpable mass. With one type of equipment, the patient lies face down on an examining table with a hole in it that allows the breast to hang through; the x-ray machine and the maneuverable needle “gun” are set up underneath. Alternatively, specialized stereotactic equipment can be attached to a standard mammography machine.

The breast is x-rayed from two different angle, and a computer plots the exact position of the suspicious area. (Because only a small area of the breast is exposed to the radiation, the doses are similar to those from standard mammography.) Once the target is clearly identified, the radiologist positions the gun and advances the biopsy needle into the lesion. This type of biopsy is typically not used in Robeson County. It is, however, used at larger medical centers.

2.6 Treatment of Breast Cancer

2.6.1 Methods of Treatment

Methods of treatment for breast cancer are *local* or *systemic.* Local treatments are used to remove, destroy, or control the cancer cells in a specific area. *Surgery* and *radiation therapy* are local treatments. Systemic treatments are used to destroy or control cancer cells all over the body. *Chemotherapy* and *hormone therapy* are systemic treatments. A patient may have just one form of treatment or a combination, depending on her needs.

Surgery is the most common treatment for breast cancer. An operation to remove the breast is a *mastectomy;* an operation to remove the cancer but not the breast is called breast-sparing surgery. Breast-sparing surgery usually is followed by radiation therapy to destroy any cancer cells that may remain in the area. In most cases, the surgeon also removes lymph nodes under the arm to help determine the stage of the disease or to examine the nodes to see if cancer may have spread there.

Several types of surgery are used to treat breast cancer. The doctor can explain them in detail and can tell the patient how each will affect her appearance.

- In lumpectomy, the surgeon removes just the breast lump and a margin of normal tissue around it.
- In partial (segmental) mastectomy, the tumor, some of the normal breast tissue around it, and the lining over the chest muscles below the tumor are removed.
- In total (simple) mastectomy, removes only the breast and areola.
- In modified radical mastectomy, the surgeon removes the breast, some of the lymph nodes under the arm, and the lining over the chest muscles. Sometimes the smaller of the two chest muscles is removed.
- In radical mastectomy (also called Halsted radical mastectomy), the surgeon removes the breast, the chest muscles, all of the lymph nodes under the arm, and some additional fat and skin. This operation was the standard one for many years, but it is seldom used now.

In **radiation therapy** (also called radiotherapy), high-energy rays are used to damage cancer cells and stop them from growing. Radiation may come from a machine outside the body (external radiation). It can also come from radioactive materials placed directly in the breast in thin plastic tubes (implant radiation). Sometimes the patient receives both kinds of radiation therapy.

Patients go to the hospital or clinic each day for external radiation treatments. When this therapy follows breast-sparing surgery, the treatments are given 5 days a week for 5 to 7 weeks. At the end of that time, an extra “boost” of radiation is often given to the tumor site. The boost may be either external or internal (using an implant). Patients stay in the hospital for a short time for implant radiation.

Chemotherapy is the use of drugs to kill cancer cells. In most cases, breast cancer is treated with a combination of drugs. The drugs may be given by mouth or by injection into a vein or muscle. Either way, chemotherapy is a systemic therapy, because the drugs enter the bloodstream and travel through the body.

Chemotherapy is given in cycles: a treatment period followed by a recovery period, then another treatment, and so on. Most patients have chemotherapy in an outpatient part of the hospital, at the doctor’s office, or at home. Depending on which drugs are given and the woman’s general health, however, the woman may need to stay in the hospital during her treatment.

Hormone therapy is used to keep cancer cells from getting the hormones they need to grow. This treatment may include the use of drugs that change the way hormones work or surgery to remove the ovaries, which make hormones. Like chemotherapy, hormone therapy is a systemic treatment; it can affect cancer cells throughout the body.

Patients may want to ask these questions about chemotherapy or hormone therapy:

- Why do I need this treatment?

- What drugs will I be taking? What will they do?

- Will I have side effects? What can I do about them?

- How long will I be on this treatment?

2.7 Early Detection

When breast cancer is found and treated early, a woman has more treatment choices and a good chance of a complete recovery. So it is important to detect breast cancer as early as possible. The National Cancer Institute encourages women to take an active part in early detection. They should talk with their doctor about this disease, the symptoms to watch for, and an appropriate schedule of checkups. The doctor's advice will be based on the woman's age, medical history, and other factors.

Women should ask the doctor about:

- **Mammograms (x-rays of the breast);**

- **Clinical breast exam (CBE) by a doctor or nurse; and**

- **Breast self-examination (BSE).**

2.7.1 Mammogram

A mammogram is a special kind of x-ray. It is different from a chest x-ray or x-rays of other parts of the body.

Mammography involves two x-rays of each breast, one taken from the side and one from the top. The breast must be squeezed between two plates for the pictures to be clear. While this squeezing may be a bit uncomfortable, it lasts only a few seconds. In many cases, mammograms can show breast tumors before they cause symptoms or can be felt. A mammogram can also show small deposits of calcium in the breast.

Mammography should be done only by specially trained people using machines designed just for taking x-rays of the breast. The pictures should be checked by a qualified *radiologist.* Women should talk with their doctor or call the Cancer Information Service for help in finding out where to get a high quality mammogram.

Mammography is an excellent tool, but we know that it cannot find every abnormal area in the breast. Thus, another important step in early detection is for women to have their breasts examined regularly by a doctor, nurse, or Clinical Breast Exam (CBE).

2.7.2 Things to Remember When Scheduling Your Mammogram

Dress

1. Comfortable

2. Preferably a 2-piece outfit

Do Not Use:

1. Deodorant

2. Talcum powder

3. Ointment

4. Creams on your underarms or breasts

5. Cut out or cut back the use of caffeinated beverages (colas, coffees, teas)

Scheduling

1. Remember to schedule for the week after your period

2. If you have had previous mammograms at another facility, be sure to bring in the address and telephone number.

Recommended guidelines for mammography:

- Initial screening mammogram at age 40.

- Annually for all women age 40 and over.

Women should always consult with their physician if they have concern for specific risk factors.

The American Cancer Society does not set an upper age limit for mammography and has firmly stated that as long as a woman is in good health, she should be screened regularly for breast cancer.

2.7.3 Clinical Breast Exam

During regular health checkups, a woman should have a clinical breast examination. The health care provider should inspect her breasts looking for changes in shape or unusual contour, spontaneous nipple discharge, skin dimpling, or other changes. After the visual exam, the area of the breasts, chest, and armpits should be palpated thoroughly to check for lumps or thickening.

At this time, a woman should observe how the health care provider carries out the clinical breast exam, especially the amount of pressure applied. It is a good opportunity for her to ask for a description of what the health care provider feels, whether any changes are noted from the last exam, and other questions related to the current exam. A woman should also talk to her health care provider about her own risk for breast cancer and how often she should have a clinical breast examination.

The American Cancer Society recommends that:

- Women age 20 to 40 should have a clinical breast exam every 3 years.

- All women over age 40 should have an annual breast exam.

2.8 Breast Self Examination Instruction Guide

2.8.1 Introduction

A woman's first line of defense against breast cancer is breast self examination (BSE). Since most breast lumps are discovered by the woman herself, it becomes clear that routine monthly breast self exams can play a key role in early detection of breast cancer. Early detection is the key; therefore, breast cancer prevention begins at home.

2.8.2 Why

It is a known fact that many women with breast cancer find their own tumors. Women who practice BSE find tumors at earlier stages than women who do not practice BSE. A woman's breast changes its shape and size throughout her life. The size, shape and feel of a woman's breast are influenced by childbirth, monthly menstrual cycles, breast feeding, birth control pills or hormone replacement therapy, menopause, weight changes and age. Thus, it is important that women become familiar with their breast.

2.8.3 What

BSE is performed to identify any unusual changes that may have taken place in a woman's breast. When examining her breast, she is looking for a lump or an unusual thickening that feels different from the rest of her breast. She should also check for changes in skin color dimplihg or skin puckering of the breast.

2.8.4 Where

BSE is completed in three phases. The first phase is simply an eye examination. It is completed by standing in front of a mirror that is large enough to see both breasts with arms at your side. Carefully examine both breasts, looking for anything unusual (as mentioned above). Examine the skin, noting any differences in the contour or shape of your breasts. Lastly, examine the nipple for any abnormal discharge. To further examine the breast clasp your arms behind your head once again checking for a change in contour and shape. Next, with your hands on your hips and knees bent slightly forward towards the mirror, examine your breasts as you pull your shoulders and elbows forward.

The second phase of BSE should be completed while the skin is slippery and wet (in the shower or while bathing). Completing BSE while the skin is wet allows the fingertips to glide gently over the skin.

The third and final phase of BSE is completed while laying down with a rolled towel or small pillow placed in the small of the back.

2.8.5 How

Completing BSE while in the shower or while the skin is wet is done by placing one arm behind the head and using the fingers of the other hand to do the palpation. Using the pads of your three center fingers, make three small circles (about the size of a dime) feeling gently on the surface, then a little firmer and finally circling deepest into your breast tissue. Without picking up your hand let your fingers “walk” to the next area. This action should continue in a circular format until the entire breast is covered. The next step would require to switch arms and perform the examination on the other breast. The entire breast should carefully be examined. Extra attention should be paid to the top portion of the breast near the underarm. Be sure to check the entire breast area, this includes the underarm area and the area around the collar bone.

2.8.6 When

BSE should be performed around the same time every month. If you are premenopausal, perform BSE seven days after the last day of your cycle. If you are postmenopausal, BSE can be done anytime during the month that is easy for you to remember (i.e., the first day of the month or your payday). In addition, all three components of BSE do not have to be completed on the same day or the same time. The first portion may be completed in the morning before work and the remainder of the exam may be done the next day.

2.8.7 Additional Notes of Importance

Each woman’s breasts are different, no two look or feel the same. Therefore, getting to know the feel of a woman’s breasts is important. The first month that you practice BSE it may be helpful for you to practice every day for a week. This will familiarize you with the feel of your breasts. It will also allow you to mentally note the areas of your

breasts that are normally thick or lumpy. When a lump is found, do not panic. Most lumps that are found are not cancerous. However, only a doctor can make this judgement. It is better to be safe than sorry. Anytime you notice anything unusual call your doctor. After feeling her breast and gaining an idea of what is normal for her, BSE should only be conducted once a month.

2.9 Risk Factors

Simply being a woman and getting older puts you at risk for developing breast cancer. The older you are, the greater your chance of getting breast cancer. The breast cancer incidence rate increases for women 65 and older, when the rate is two times higher.

Risks also increase for women who have a family history of breast cancer. The mothers, daughters, and sisters of women with breast cancer, especially if the relative developed this cancer at an early age (45 or younger), are two to five times more likely to develop breast cancer themselves than are women without a family history.

Women who themselves have already had cancer in one breast also run an increased risk of developing cancer in the other breast.

To a lesser extent, risk is influenced by a woman's reproductive history. Risk is increased for women who began menstruating earlier (before age 12, compared to after 15), had their first child later (after age 30, compared to before 20) or were never pregnant, or completed menopause later (after age 55 compared to women who had their ovaries removed -- a "surgical menopause" -- at age 45).

Risk is also increased for women who are overweight, especially those who carry excess fat in the upper body -- abdomen, shoulders, nape of the neck. As noted above, risk is increased moderately for women who have the benign breast changes known as atypical hyperplasia.

Many aspects of the American lifestyle are suspected of possibly influencing the growlng incidence of breast cancer. Current research is looking into the roles of obesity, hormones, and fat metabolism; the risks and benefits of postmenopausal hormone replacement therapy; the impact of taking oral contraceptives at an early age and for many years; alcohol

use; and diet. Caffeine, on the other hand, appears to have no influence on the incidence of breast cancer.

It is important to keep in mind that these factors that increase cancer risk -- **risk factors** -- do not necessarily cause cancer; they are merely associations. Having one or more does not mean that you are certain or even likely to develop breast cancer. Even among women with a strong family history -- both a mother and a sister or two sisters, one of whom developed breast cancer in both breasts or before menopause -- three-fourths will not develop breast cancer.

Not having any of the known risk factors, on the other hand does not mean that one is "safe." The majority of women who develop breast cancer do not have a family history of breast cancer and do not fall into any other special high-risk category. (See Appendix D for Breast Cancer Resources)

2.10 Facts About Breast Cancer in the USA

- Breast cancer is the most common form of cancer in women in the United States. It occurs rarely in men. Both its cause and the means for its cure remain undiscovered. Nearly two million breast cancer survivors are alive in America today.

- In 1998, 178,700 new cases of female breast cancer will be diagnosed, and 43,500 women will die from the disease. Breast cancer is the second leading cause of cancer death for African-Ameritan women, and the leading cause of cancer death for all women between ages of 35 and 54.

- One out of eight women in the United States will develop breast cancer in her lifetime -- a risk that was one out of 14 in 1960. This year, a breast cancer will be newly diagnosed every three minutes, and a woman will die from breast cancer every 12 minutes.

- **Every woman is at risk for breast cancer.** The risk of developing breast cancer increases as a woman ages, if she has a family history of breast cancer, has never had children or had her first child after age 30. However, over 70% of cases occur in women who have no identifiable risk factors.

- Breast cancer cannot be preverited, but it can be detected at an early, treatable stage. Fewer than half of women age 40 and older in the United States have regular screening mammograms, a simple procedure that can reveal breast cancer at its earliest stage, up to two years before it can be felt. It is agreed that regular screening mammography should begin by age 40 and be annual after age 50.

- Regular breast examinations by a medical professional are a required complement to screening mammography. Many breast irregularities are found by women themselves, yet women often do not know how to perform breast self-examinations (BSE), and few do so regularly. Although it has never been proven to affect survival, monthly BSE is the third recommended component of each woman's breast health program.

- Over 80% of breast lumps are proven benign, but any breast lump must be evaluated by a physician. Follow-up biopsy is often recommended.

- If detected early, breast cancer can often be treated effectively with surgery that preserves the breast, followed by radiation therapy. This local therapy is sometimes accompanied by systemic chemotherapy and/or hormonal therapy. Five-year survival after treatment for early-stage breast cancer is over 90%.

- Breast cancer incidence increases with age, rising sharply after age 40. Close to 80% of all breast cancers occur in women over 50 years of age.

2.11 What is Your Risk of Developing Breast Cancer?

By age 25	one in 19,608
By age 30	one in 2,525
By age 35	one in 622
By age 40	one in 217
By age 45	one in 93
By age 50	one in 50
By age 55	one in 33
By age 60	one in 24
By age 65	one in 17
By age 70	one in 14
By age 75	one in 11
By age 80	one in 10
By age 85	one in 9
Ever	one in 8

The mortality rate from breast cancer would decrease by 30% if every woman over 50 received regular mammograms, CBE and performed BSE.

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CHAPTER 3

The Role of the Community Health Educator

3.1 What is a Community Health Educator (CHE)?

Community Health Educators (CHE) are people who reside in the community and have received training to assist women in the community to take better care of themselves. A CHE is a person with natural skills in helping and assisting people and thus may be considered a community leader.

3.2 What Role Does the CHE Have in the ROSE Project?

The CHE has a vital role in the project. The success of the intervention is totally **dependent** upon the abilities, diligente and hard work of the CHE. Specifically listed, the roles are as follows:

1. To serve as a link between the Robeson Health Care Corporation (RHCC), the project and the participant.

2. To educate participants on the importance of early detection for breast cancer.

3. To create an awareness of the Centers of Disease Control Breast and Cervical Cancer Control program (Wise Woman Program), which provides low or no-cost mammograms.

4. To provide counseling for participants on barriers to getting mammograms and practicing early detection for breast cancer.

5. To serve as a friend, educator, counselor and cheerleader for the participant as she seeks to learn about breast care and receive her mammogram.

6. To keep extensive records with personal information on each participant (birthdays, and other important pieces of information).

7. To provide emotional support, always understanding and listening with concern.

8. To assist the participant in making appropriate transportation arrangements as they are available in Robeson County.

One of the most important roles of the CHE is to advocate change. As a CHE your concern is always what's best for the participant. You are interested in making sure that she is doing all that she can to take care of herself. Often this may mean encouraging the woman to ask questions and make suggestions regarding her health when speaking with her health care provider.

3.3 Ways to be an Effective Community Health Educator

The women who will receive the intervention will come from a variety of backgrounds. The following provides a discussion of possible situations that you may encounter and suggestions on how to handle them.

3.3.1 Going Along to Get Along

Often participants will PRETEND to have interest in what you have to say just because they feel that it is what they are supposed to do. Phony interest is not what we are trying to capture. We are interested in making a lasting change in the lies of these women. Thus, you must be sensitive to the attitudes, body language, responses and interest of each participant.

***ATTITUDE:** a negative attitude or one of "not wanting to be bothered" can in itself be a barrier. It is your ultimate goal to find out what will motivate this woman to become interested in what you have to say. You may find that for one participant it may be "living to see her children or grandchildren grow up," for another it may be that "she must stay healthy so that she can continue to work," for yet another it may be "her personal religious belief."

***BODY LANGUAGE:** how one carries herself can say a lot about how she feels and the interest level in what you have to say. Crossed arms will signal a defensive attitude or even one of self protection. Lack of eye contact may signal a lack of trust or lack of interest. Accepting body language may vary from culture to culture. As an example, in the African-Ameritan culture, eye to eye contact is expected and is a way of showing respect. In the Native American culture, that may not be the case.

***INTEREST:** You have most likely lost the participant interest when she has become restless and her eyes have lost contact with yours. You must remain alert to changes such as these so that you may alter your strategy as necessary.

3.3.2 The Tendency to Stray From the Topic

Some of the participants will more than welcome the opportunity to have someone to talk to who cares. Participants will attempt to explain their situations and discuss their problems. While, we are concerned about the participant's overall welfare, we are there primarily to administer the project's intervention and move on to other duties and visits. **Be careful not to offer personal counseling outside of the purpose of your visit.**

3.3.3 Difficulty Understanding the Information

Some of your participants may have difficulty understanding the information that you are sharing. You must always be aware that some of your participants may not be able to read. **This can be detected by handing a pamphlet to the participant upside down and the participant does not turn the pamphlet right side up.** Once this is noticed, you must be very careful never to embarrass or make the participant feel uncomfortable or ignorant. Instead, attempt to carefully summarize the information that was to be read by the participant and continue with the intervention. **This should be noted on the person's personal information card and encounter form.**

3.3.4 Fear of Being Victimized

Some of your participants may refuse to allow you into their homes to conduct the intervention because they may be afraid that your interest may not be honest or sincere. It is your responsibility to assure them that your intentions are honest and to make them feel secure. Your identification badge and letter will assist you in reassuring the participant, convincing them of your purpose and fostering a trusting atmosphere. Fostering an atmosphere of trust is very important. The participant will be more comfortable with you and better able to discuss her concerns regarding breast care.

3.4 Effective Means of Assisting Adults Learn

The majority of us (adults) learn through informal means. Most of us have long gone beyond the classroom experience. Informal learning is done "by doing, observing, reading, watching television, asking questions, and talking with others." No one method of learning is better than or yields better results than the other. However, long lasting, habit changing learning will use most of these methods. Since one method of learning may appeal more to one person than another, it is important to be observant and quick to adapt. For example, if you notice that you have lost the attention of the participant after a few minutes of talking, it may be time to change and ask questions to involve the participant. You will find that you will be more successful when you do not lecture the participant for the entire session.

Think of your sessions with each participant as a "***SHARING SESSION***." A time when you can come and share the project's intervention and the participant can share how she feels she may or may not be affected by the information that you are sharing. The overall goal of each of the visits is to teach the woman about good breast care so that her attitudes, lifestyle and habits will change.

3.5 What Must Be Present to Create These Changes?

In order to promote and encourage healthy breast care habits, the CHE must utilize the following techniques:

1) **Motivation:** In order for the desired changes to occur the participant must be motivated. She must be encouraged to seek

the benefits. The information must be applicable or "real world." Motivation is increased when:

a) Constant encouragement is used and participation is encouraged.
b) Recognition is given for achievements.
c) Encourage participant to take charge of her life using the newly learned information.

2) **Conditioning:** Bad habits, bad advice and myths have often caused us to practice (or not practice) good health behaviors. These habits, advice, and myths must be undone in the participant's mind. As a CHE it is your job to provide a non-threatening atmosphere that will allow honesty and open sharing. It is through this type of sharing that you will gain understanding of the participant.

3) **Repetition:** In this sense, repetition does not mean saying the same thing over and over in an attempt to memorize. It is meant to encourage you to state the most important facts several times, each time using a different manner. As an example, consider the following: after explaining the mammography guidelines using the video/flip chart, the information will be reinforced by leaving a brochure that shares the same information. Reinforcement of important facts will greatly increase the likelihood of a good learning experience.

4) **Attention:** Most people can concentrate on one thing at a time. Thus, you must create an atmosphere where you are the center of attention. If you walk into the home of a participant and the television or radio are an obvious distraction, politely request that it be turned off. In order to receive the desired results from our educational sessions information must be obtained in an atmosphere that is quiet with as few distractions as possible. You should also request privacy (no one else in the room) if at all possible.

5) **Individual Differences:** People learn in different ways at different rates. One person may grasp information quickly while others may take a little longer. It is your responsibility to make sure that every **ROSE** participant grasps <u>all</u> of the desired information. This

may require you to spend more time with one participant going over the same information while finishing early with another.

6) **Using What Is Learned:** Unless what you've learned is quickly applied (especially when the information is new) it will be forgotten. Therefore, we must encourage quick response. If you have just com'pleted a session on mammography (what it is and what is to be expected) then the participant should be encouraged to schedule her appointment while the information is fresh. It will be helpful to the participant if you offer to assist in scheduling while you are still with the participant.

7) **Trust, Emotions and Learning:** When we are fearful, mistrusting and tense we are unlikely to retain the information being shared. Thus, you must spend the first few minutes building and confirming trust. This can be done by discussing things that the participant is knowledgeable about and comfortable with. If you notice that the participant enjoys knitting then this may be a good ice breaker for this participant. Once you begin sharing information about early detection, it is important to also share the benefits. Since fear is often the first emotion evoked when breast cancer is mentioned, discussing the benefits will help lessen the fear.

Remember: *As CHE's for the ROSE Project you are the most important people; the success of the project depends on you! Your ability to motivate and encourage will not only prove the project to be successful but will assist in saving lies.*

3.6 Your ROSE Assignment Overview

This section of the manual is to provide an overview of your assignment for the **ROSE** Project.

3.7 Terminology

There are some terms used throughout this manual that have, for purposes of this study, exact meanings which refer to specific project forms or materials.

- **Sample Member:** Female, 40 years old or older, who resides in Robeson County, is a patient of Robeson Health Care Corporation. Only one sample member may be selected from each sample household.

- **Respondent:** An eligible person who has been selected to be contacted and who actually answered the questions posed by an interviewer.

- **Record of Contacts Sheet:** A form on which the interviewer recorded the attempts to contact a sampled household and the outcome of each attempt.

- **The Baseline Women's Survey:** The data collection instrument administered to eligible sample members. This questionnaire provides sections on respondent's health, tobacco exposure, demographics, and tracing.

- **Respondent Information Sheet:** A form on which the interviewer recorded the names and addresses of three persons (family, friend, neighbor) who will know how to reach the respondent.

- **Informed Consent Statement:** By signing this form the respondent agreed to participate in the study. It told the respondent what the study was about and about her involvement in the study. This form was read to the respondent if necessary and emphasized that her participation was strictly voluntary. Once the respondent signed on the participant line, the interviewer signed on the witness line. If a respondent could not read or write her name, she marked with an (X). The interviewer signed her name beside the (X). A copy of the consent statement was left with the participant.

- **Consent To Release Medical Information:** By signing this form the respondent has agreed to participate in the study and to authorize their health care provider to disclose to the project, information from their medical record pertaining to screening tests or procedures.

- **Community Health Educator Identification Letter:** A letter, on **ROSE** letterhead, identifying you as an authorized representative

of the study. You should carry this letter with you at all times while you are in the field.

3.8 Role of the Interviewer

The interviewer's goal is to collect accurate information using the survey forms according to sound interviewing practices. The interviewer is a vital link between the respondent and goals of the study. Interviewers prepared not only to elicit information and record it accurately, but also to give information when necessary. Interviewers have the important responsibility to establish good rapport between **ROSE** and the respondents.

3.8.1 Summary of Interviewer Duties

Field work will begin immediately after the week of interviewer training. Although some sample members will be available during the day, some of their field work will take place during the late afternoon and evening hours on weekdays and on weekends.
Interviewer principie fieldwork duties are summarized below:

1) Before leaving the training session, they will understand their assignment and check to be certain they have all the necessary materials and supplies.

2) Before beginning their work in an area, they will make a quick check of the area to be sure they have correctly located the correct area and the listed sample member's household.

3) They will contact each sample member in their assignment area and record unsuccessful efforts and results and explain in detail.

4) They will contact randomized sample members that they have been assigned and request their participation. If they agree, their first visit will be scheduled. If necessary, they will make up to **five** attempts to contact the sample member and schedule the first visit. Unless they have been informed that the sample member is unavailable evenings and

weekends, at least three attempts must be made during those times. They must record the efforts expended and the results obtained in the Record of Contacts.

5) They will field-edit all completed forms so that they are error-free when returned to their supervisor.

6) They will record the status of their efforts for each sample member on the Record of Contacts Form.

7) They will report the status of each assigned case to their supervisor during their regular contact.

8) They will call their supervisor if they encounter problems that they cannot resolve and that require immediate resolution.

9) They will record daily their production, expenses, and time on the form(s) provided by their supervisor.

10) **All work will be randomly selected for verification by supervisory staff.**

3.9 Materials Supplied

At your training session, you will be provided with the following materials for use in completing your fieldwork assignment:

1) A copy of this manual for training and subsequent reference.

2) A local map

3) Your Community Health Educator Identification Letter

4) Lists of Advisory Board Members

5) Local newspaper clippings

6) **ROSE** Door hangers

7) A supply of forms and materials to be used to deliver the intervention. These include:

- Encounter Forms for Visits One, Two, Three, Other Contacts and Nonparticipants
- ROSE Personal Data Cards
- Appointment cards

8) A note pad

9) A supply of black ball point pens

10) A supply of Production, Expense and Time Report Forms, Work Status Report forms, and Weekly Travel Log forms.

11) A hand held tape recorder to be used to record dates, times, places and questions as they are fielded. This will allow CHE's to keep accurate records so that contamination can be monitored.

12) A Cellular Telephone to be used for **ROSE** Project calls when a regular telephone is not available.

You will have full responsibility for all the study materials issued to you. All materials must be returned to your field center when your assignment has been completed and you are instructed to do so by your supervisor.

3.10 Standards of Performance for Community Health Educators (CHE):

The success of this project depends on each CHE delivering accurate information and getting and recording <u>accurate</u> and <u>complete</u> information. Otherwise, no amount of review or correction can improve the reliability of the results. Equally important, if you do not complete your assignment efficiently and in the prescribed time period, the project cannot be conducted within the budgetary and scheduling constraints.

ROSE staff have determined, based on past experience gained in similar projects, the amount of time required to complete each assignment accurately at a reasonable working pace. This standard, which includes time for travel, completing necessary visits and other required activities, will be compared with

the amount of time you actually take for your assignment to see how efficiently you are performing your work.

The time and mileage spent in traveling to and from the sample member's home is one of the major costs of a project such as **ROSE.** Hold travel to a minimum by carefully planning your route and the order in which you visit sample participant's homes. You can also minimize callbacks by planning your initial visits at the most productive time and by tying in callbacks and other visits with remaining initial visits to the area. When a sample member is not at home or available on your scheduled first visit, call back to reschedule based on study guidelines.

Another time saver is the efficient conduct of the sessions. If you are thoroughly familiar with the materials and forms, you can conduct the visits rapidly and efficiently without sacrificing accuracy. Also, be prepared to explain the purpose of the study and related subjects, briefly, and clearly.

No matter how efficiently the education sessions are conducted, the results may be seriously affected by incomplete, or inaccurate documentation. In rating CHEs, the quality of your work is given as much weight as your productivity. This manual contains detailed instructions on how to execute your assignment. Learn how to use these resources and refer to them as necessary during your fieldwork. Call your supervisor if you encounter a problem with these materials that requires immediate resolution.

You will be kept informed of how your performance compares with the established standards for efficiency and quality, and how you may improve your performance.

3.11 Confidentiality

The identities of the participants, respondents and the information they provide are **confidential** and must not be divulged to anyone other than authorized study representatives. To be certain that you understand and agree to the confidentiality requirements of this study, you will be asked to review and sign a contractual agreement to this effect at your training session.

When conducting the intervention, **emphasize confidentiality** to participants during your introduction. Remind the participant that she is free to ask any question at any time. Also, during any educational session, emphasize

confidentiality and/or show the respondent a copy of your confidentiality oath when necessary.

You must exercise care to protect the identity of participants and the information they provide. Completed or unused intervention forms and materials are not to be shown to anyone other than authorized project staff and duplication of materials is not permitted. Visits must be conducted in private whenever possible.

3.12 Verification of the Fieldwork

Because of the importance of this study, your fieldwork will be thoroughly verified by ROSE staff. Aspects of the administration of the intervention will be verified in detail. When thanking each respondent for her cooperation during visit one, tell her that she may be contacted by your supervisor to verify your work. Remember each CHE must strive to meet the major goal for each visit. If you have not been successful, additional follow-up may be necessary (by phone or in person). Please discuss these situations as they arise with your supervisor.

3.13 Field Edits

There are two edits that you are required to perform following completion of an education session. They are described in this section.

3.13.1 After Leaving the Participant's Home

Immediately following completion of an educational session/call or contact, you should take a few minutes to review what has happened. You may want to use the tape recorder to note what happened. Make certain that you legibly and accurately complete all required forms. There must be an entry for every required section. If you discover that you have omitted some information, or if you note any inconsistencies, obtain the missing information or resolve the discrepancy as soon as posible. Also, make sure all times have been recorded on the Encounter Form and that, you have recorded any CHE Comments.

3.13.2 Later - At Your Home

The second step is a thorough review at home. In order for your final edit to be successful, it must be performed while the educational session is still fresh in your mind. After a number of sessions, the respondents and the specific characteristics of each session tend to blend together, so the final edit of all completed forms must be performed as soon as possible after the session. Again, all forms and documentation should be completely edited on the day the session occurred. In petforming your edit, be sure that the edits conform to the instructions in this manual concerning the completion of all items on the form. Pay special attention to the following checks:

- ✓ As you complete all forms, be sure that there is a response recorded for every required item.

- ✓ All entries should be legible, not just to the CHE who wrote them, but to others who will read the documentation. Abbreviated words should be spelled out if they are not standard abbreviations.

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Handling Other Intervention Issues

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CHAPTER 4

Handling Other Intervention Issues

4.1 How to Handle Telephone Refusals

Reaching ROSE participants by phone may become a difficult task. However, every effort must be made to reach every participant.

The following are the required steps to reaching a participant who has a telephone.

1. Six attempts on different days of the week (weekends included) at different times of the day. (Be sure to note a.m. or p.m. on your forms.)

2. After 6 attempts, mail the participant a call requesting that she call you.

3. If after one week you have not received a response, visit the participant's home. Try 2 visits at different times of the day.

4.2 Participant Without a Telephone

If the participant doesn't have a telephone where she can be reached the following is suggested.

1. Double check, to make sure there is no additional number listed to reach the participant.

2. Mail participant a handwritten (printed) note card requesting that she call **you.**

3. **If after one week no response has been received, attempt 2 in person visits. (Each at different times of the day.)**

4.3 How to Handle Refusals

Regardless of how hard we try or how easy we are to get along with, there will be participants who will refuse to allow you to deliver or administer the intervention. Because we feel that we are offering the participant a wonderful opportunity we must try to get through whatever excuses or barriers that she may try to use.

4.3.1 By Telephone

Excuses and barriers are easy to place over the phone since there is no person to person contact. Prior to your call, the participant will have been contacted by other members of the study thus, **ROSE** will not be a stranger.

4.3.2 When Scheduling

If you receive a refusal while trying to schedule an appointment, assess why. If the participant is refusing because of the time or day of either the appointment or your call offer to call again at a better time (be sure to ask what time would be better). If the refusal is due to the time the visit has been scheduled, offer to reschedule at a better time. The participant may ask how long the visit will take? Offer only approximate times and state that visit times will vary depending upon how much information you have to go over. She may reply “I don’t have that much time,” on that day. Once again offer to reschedule at another time.

4.3.3 In Person

Even after you have scheduled the appointment and verified the date and time with a follow-up call, you may still receive a refusal in person.

If you arrive at a participant’s home and the participant is not home, then call back at another time to reschedule.

If you are at the participant’s home and no one is home, leave the **ROSE** door hanger. Allow the participant a day

or two to call you back and if no response, call the participant once again.

The participant may answer the door and inform you that she has changed her mind. Attempt to determine why she has changed her mind. Address the reasons and remind the woman of the invaluable information that will be given to her in person and that a gift will be left for simply listening. Proceed to complete the visit as best you can. Document the visit on the appropriate encounter form making sure to note any change from the usual visit format.

4.3.4 Types of Refusals

* **Already Getting Health Information**

The women may also say that she receives all of the health information that she needs from her doctor. Tell the participant her doctor should always be her main source of health information and that you are not trying to replace that. What you CAN provide for her is important health information right in her own home. She won't have to worry about being rushed or treated rudely. In addition, the information that you have to share has been created just for her.

* **Just Not Interested**

The participant might even say that she just isn't interested. You will want to take the emphasis off the participant and place the emphasis oh the others that are in her life and are important to her ". . . well, if you are not interested in hearing this information for you, then hear for your husband, children, or all the others in your life that depend on you."

4.3.5 Free Incentives

Never underestimate the importance of receiving something free. Always mention that for each visit the participant will receive a nice free gift as a thank-you for her participation.

Finally, stress to the participant that we (or you) care about her and want to make sure that she is well informed. By allowing you to share with her she will also receive information that she can pass on to other women in her family.

4.3.6 Passive Refusals

Whether in person or by phone, you may find that some participants will continuously put you off and never actually schedule the visit. After politely attempting to schedule a visit, simply dropping in at a time when you have previously found the participant to be at home may be required. Upon arrival, you may simply tell the participant that you were in the area and are ready to conduct your visit (without giving them opportunity to refuse).

4.3.7 When All Else Fails

Unfortunately, everyone is not going to have a change of heart even after you have provided several other options. Even so, we cannot afford to lose one participant. Sometimes, all that is needed is a change of approach. **Difficult cases should be discussed with the health education coordinator at your weekly meeting. At which time, the two of you can decide which steps should be taken next. In most cases another CHE or the assistant project manager will be asked to assist with the case, but first discuss the case with your supervisor.**

4.4 Contamination

As the word spreads about the project and how great the information is that you are sharing, you may be approached by other women who are just curious about what ROSE is all about. We must be careful not to provide information to those women not enrolled in the **ROSE** intervention group, so that the effect of the intervention can be measured. Thus, any woman who has not been selected by the project to receive the intervention **SHOULD NOT** receive any of the intervention (both written materials and through discussion). We always want to be friendly and

helpful with anyone in the community; therefore, your response must be carefully and cautiously given. Consider the following responses:

"Ms._____ , I'm so glad that you are interested in learning more about breast cancer. However, we must be careful to provide you with the information that best suits your medical history. I would suggest your making a list of all of your questions and asking your doctor or nurse at your next visit."

"Ms._____ , I'm really happy that you're interested in learning about mammography and breast care. In general, let me refer you to the Wise Woman Program here in the county. They are a wonderful source of information and can help you schedule your appointment."

"Ms._____ , **ROSE** is a project that works with selected women who are patients at RH'CC. Your name may not have been chosen by the computer to participate. If you are interested in learning more about inammography why don't you give the ladies at Wise Woman a call."

Anytime a CHE is faced with being questioned either about the Project or about breast cancer the CHE is to immediately record the incident using the handheld tape recorder. The incident should be documented on the Nonparticipant Encounter Form.

4.5 Intervention Tailoring

Intervention tailoring is done anytime that you accent the intervention plan that is being used. Tailoring allows you to make the intervention more suited to the participant. It may become necessary to tailor the intervention program to address needs and barriers specific to a particular individual or ethnic group. **Tailoring should not change the basic message we are delivering.** Tailoring simply allows the methods to change to best get the point across. As you visit the homes of the participants and assess the woman's knowledge, interest and personal barriers you may see the need to provide additional information and encouragement.

We are able to provide tailored intervention through the following ways:

Barrier Counseling:	Through the use of the Barrier Counseling form you will be able to tailor the discussion towards the participant. Once the barriers are assessed, you will be able to target your discussion towards the apprehensions of the participant in an attempt to obtain regular mammography screening.
Educational Materials:	All educational materials used by the CHE will be culturally and age appropriate. Since ROSE is being utilized by women of three different ethnic groups, it is important that the CHE use the educational pieces that have been selected for each group.

While providing tailored intervention to participants, it is NEVER to be done without prior consent of your supervisor. Each visit is to be conducted as laid out during training and as specified in the CHE training manual. If at the end of a visit reinforcement becomes necessary, it is to be done at another time.

Chapter 5
Beginning Intervention and Visit One

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CHAPTER 5

Beginning Intervention and Visit One

5.1 Tracking & Scheduling Participants

Each **ROSE** participant is an important part of the study and we need to do all that we can to ensure that she receives all parts of the intervention. The following provides you with the scheduling and tracking procedures:

1. A woman is randomized to the intervention portion of the study.
2. Her Record of Contact Sheet, Informed Consent Statement, Forms and Respondent Information Sheets are given to the Health Education Coordinator.
3. The Health Education Coordinator assigns participants to the appropriate CHE. The approximate intervention dates will be noted to serve as a reminder for both the Health Education Coordinator and the CHE.
4. The approximate intervention dates are added to the CHE's calendar to serve as a reminder. This system will assist in making sure that no participant is lost and all appropriate intervention is received.
5. Once the approximate intervention dates are recorded the participant's intervention file is begun. The first items to be included are copies of the Informed Consent Statement, Record of Contacts Form, Respondent Information Sheet and the Encounter Forms (originals will be kept in Winston-Salem). On the inside cover of the file a check-list is to be included and continuously up-dated. It is the responsibility of each CHE to maintain complete and accurate documentation in the participant's file. It will be checked periodically by your supervisor.
6. At this point the CHE is ready to place the call to schedule the initial visit (Visit One).

5.2 Visit One: (Approximately one hour)

HOME VISIT #1
Major Goal: ***To assist the participant in understanding the importance of mammography and to assess barriers that may hinder compliance.***

1. Introductions: community health educator, about the project, and completion of a personal data card.
2. Completion of the Rose Breast Cancer Personal Risk Form
3. Completion of Barrier Assessment Form/Barrier Counseling
4. Discuss "Keeping the Circle Unbroken" brochure (brief mentioning of BSE and CBE)
5. Mammography discussion (Story of a woman getting screened) using a combination of story telling and a flip chart for visuals
6. Discuss ways to schedule an appointment (actually schedule next appointment if participant is willing)
7. Schedule next home intervention visit

Visit One is a very important visit. It should be scheduled approximately 1-2 weeks after the baseline survey. It will set the tone for the remaining visits/contacts with the participants. The first portion of the visit should be spent getting to know the participant and allowing her to get to know you. In addition to personal introductions you should also introduce the project. **REMEMBER,** always wear your badge and have your ID letter available (See Appendix F). Introductions should go as follows:

1. Personal introduction
2. Study introduction
   a. **ROSE** stands for **R**obeson **C**ounty **O**utreach **S**creening & **E**ducation **P**roject
   b. The project involves teaching a select group of women who are RHCC patients about the importance of taking care of themselves through regular Mammography, Breast Self Examinations and Clinical Breast Examination.

3. Participant Introduction
   a. Allow the participant to share or introduce herself. As she introduces herself ask questions where appropriate regarding things that she shares about herself. (IE. . . if

she shares that she enjoys canning fruit and that's an area that you're interested in share that and ask questions).

b. **ROSE** Personal Data Card should be completed as soon as Visit One is completed and placed inside the participant's file. (See Appendix E)

4. **ROSE** Breast Cancer Personal Risk Scale: This form simply takes into account the factors that may influente a woman's personal chances of getting breast cancer.
   a. Form completion: the CHE should write the correct point in the score section from the point category that corresponds to the risk factor. After adding each of the risk scores, write the total score on the total score line.
   b. Look at where the score falls to determine the woman's risk. It is important to help the participant understand that a low risk score does not eliminate the chances of getting breast cancer, nor does a high risk mean that a woman will get breast cancer. It is important to explain that this is just a way of becoming more aware of ones personal risk factors. (See Appendix E)

5. **ROSE** Barrier Assessment: This is a simple assessment that will be administered by the CHE. This assessment will allow the CHE to become aware of the underlying reasons that may be keeping a participant from getting a mammogram. Within each main reason are sentences that may summarize the participant's feelings about mammography. Once the barrier(s) is/are identified, the CHE will provide barrier counseling. (See Appendix E) Note: This form should be administered only when the CHE feels comfortable with the participant and the participant with the CHE.

6. "It Takes Three" Brochure: This is our opportunity to help the participant understand that it takes three things to ensure good breast health. During this first visit you will teach about the importance of mammography. The second visit will cover the remaining two things a woman must do (clinical breast exam [CBE] and breast self exam [BSE]).

7. Mammography Discussion (flipchart)

8. Ways to Schedule a Mammogram
    a. The participant may ask her doctor or a staff person to schedule her mammography appointment.
    b. The participant may schedule the appointment herself.
    c. Visit the mobile mammography unit
        1. Ask the participants if she would like for you to assist her in scheduling her mammogram.
        2. Leave project information about dates, locations and phone numbers to schedule an appointment for a mammogram. (See Appendix G)

9. End the Session
    a. Inform participant that the next visit will need to be within the next 2 to 3 weeks.
    b. Schedule the next visit.
    c. Complete a **ROSE** Next Visit Card
    d. Encourage participant to review the information that was shared today prior to your next visit, so that you may answer any questions that she may have. (See Appendix E)

10. Complete Visit One Encounter Form

5.3 Reporting Procedures

While providing the women of the Robeson County community a great service, **ROSE** is a research project. Thus, it is very important to keep careful documentation, detailed notes and reports. CHEs will meet on a weekly basis with the Health Education Program Coordinator (dates and times to be announced). It is at this time that following will occur:

1. The CHE should be prepared to discuss the following:
    (a) all activity completed for the previous week;
    (b) all planned activity for up-coming week;
    (c) any problems or unusual situations that may have occurred during the week and that have been noted on the encounter form
    (d) all work in progress.
2. Reports are to be turned in each week at the meetings with your supervisor. The following reports will be due: Weekly Progress Report, PET Form and your completed Bubble Card, Weekly

Travel Log, Travel Expense Voucher, and all forms completed for visits or contacts such as Encounter Forms, etc.. (See Appendix E)

3. The CHE's Personal Participant Log should be completed on a weekly basis and compared to the Health Education Coordinator's Personal Participant Log. The two logs should always agree.

Chapter 6
Visit Two

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CHAPTER 6

Visit Two

6.1 Visit Two: (Approximately one to one and a half hour)

HOME VISIT #2 ***(scheduled 2 to 3 weeks after the first visit)***	
Major Goal: ***To assist the patiicipant in understanding the importance of Clinical Breast Exam and to provide in-depth instruction on how to conduct Breast Self Exam.***	
1.	Reintroduction.
2.	Review personal barriers assessed in first visit, provide counseling as necessary.
3.	Using Risk form from previous visit, discuss risk and reinforce the need to get regular mammograms.
4.	Discuss mammography appointment (if scheduled or completed). If mammogram has not been scheduled then discussion should encourage scheduling. If a mammogram has been scheduled but not occurred then the CHE should answer any unanswered questions and provide reassurance.
5.	Using breast models demonstrate and teach BSE, the woman will be informed that she will be asked to demonstrate BSE at the next visit.
6.	Explain CBE and its importance.
7.	Discussion of healthy eating as it relates to an overall healthy lifestyle.
8.	Schedule next visit.

Visit Two is to be scheduled two to three weeks after the first visit. This visit is the last actual intervention visit until the later half of the intervention year for the participant. The overall theme for this visit places an emphasis on Breast Self Exam (BSE) and the Clinical Breast Exam (CBE). As in **Visit One**, begin this visit with a personal introduction. REMEMBER: always wear your ID badge and have the ID letter available if needed.

6.1.1 Personal Reintroduction , even though only a few days or maybe weeks have passed since **Visit One**, be sure to spend the first few minutes reintroducing yourself and the project. As if visiting with an old friend, spend a few minutes chatting and sharing. **It is important to always refer to the participant's Personal Information Card. This will provide you with things to discuss that the participant is interested in.**

6.1.2 Review

1. Always ask if the participant has gotten a mammogram since the two of you were together. If she has, this is a time for encouragement and praise (encourage her to share and discuss the experience). If not proceed with the intervention.
2. If the woman has not gotten a mammogram then review the information on mammography from the last visit. Be sure to ask the participant throughout the discussion if she has any questions and if she understands. (See Appendix G)
3. If the participant has not gotten a mammogram gently ask why. Any barriers that are mentioned should be discussed at that time. This is also a good time to recounsel her on barriers that were found in the first visit. If the participant has gotten a mammogram ask if anything occurred to prevent her from having another. It is very important that the CHE refer to the Barrier Form so that issues may be addressed.
4. Once again, offer to assist in scheduling the appointment.

6.1.3 Breast Self Examination (BSE)

1. As you begin an explanation of BSE be sure to point out that it is important that as women we must do all three (BSE, CBE and mammogram) so that any abnormality will be detected early.

2. Using the breast models, demonstrate and explain to the participant how to do BSE.
3. This will require a thorough understanding of the breast information contained in Chapter Three.
4. Allow the participant to demonstrate on the appropriate size breast model.
    1. Observe the participant as she examines the models.
    2. Make sure that she is using her fingertips.
    3. Make sure that she is not picking up her hands and skipping spaces on the model.
5. Give the participant the small boxed breast model (that she may keep) and allow her to find the lumps.

6.1.4 Clinical Breast Exam (CBE)

1. Use the explanation provided in Chapter Three to explain CBE.
2. CBE is usually conducted during a physical but can be done during any visit as requested. It is best suggested that the CBE and mammogram be done about the same time each year. If the participant sees the physician to have a CBE the mammogram can also be ordered.
3. If the participant has not gotten a good understanding of how to do BSE this is a good time to ask for assistance from the physician or nurse.

6.1.5 Healthy Lifestyles

As we are encouraging good breast care, we must also inform the participant of other areas that promote healthy living. This discussion is meant to take only the final 5 minutes of the session and is to be kept brief. As the discussion of the importance of healthy eating takes place, the CHE will leave the following brochures: Down Home Healthy Cooking, Your Best Body and Eat 5 Fruits and Vegetables a Day. These brochures will reinforce the healthy eating discussion and leave information for the participant to review at her leisure.

General Healthy Eating Facts for the CHE:

1. The average American diet is high in fat and cholesterol and low in fiber.
2. Only 1 in 10 Americans eat enough fruits and vegetables daily.
3. Being overweight leads to an increased risk for getting breast cancer.
4. We can reduce these risks by:
    1. Eating more fruits and vegetables.
    2. Eating leaner cuts of meats, low dairy products, more seafood and fewer fried foods.
    3. Increase the number of servings that you eat from the bread and cereal group; for example, brown rice, noodles, oatmeal, whole wheat bread, muffins.
    4. Eat a variety of foods that will boost your body's ability to fight disease. These are foods high in Vitamin A and Vitamin C such as carrots, yams, sweet potatoes, leafy vegetables, citrus fruits and juices made from these.
    5. Avoid too much sugar, sugary foods are often high in fats and high in calories.
    6. Avoid too much Salt. Salt is a known contributor of high blood pressure. (See Appendix G to be left with participant)

6.1.6 Ending the Session

1. Make sure the participant understood all that was discussed.
2. Provide her with an opportunity to ask questions.
3. Ask the participant if she has discussed breast cancer or breast screening with anyone since your last visit. If she has, PLEASE note this on the Encounter Form for Visit Two.
4. Inform the participant that at the next visit you would like her to demonstrate how to do BSE using her mini-breast model.
5. Instruct the participant to call you if she has a mammogram prior to your next visit or if she has any questions.
6. Discuss the remaining months of intervention.

1. Make sure the participant understands that it will be several months before your next visit.
2. Before your next visit, you will call the participant and share more helpful health information with her.
3. You will also mail her some information regarding mammography.
4. **It is important that the participant understands that even though it will be a few months before your next visit that she can call you at anytime.**
5. Explain that you will call the participant several weeks ahead of time to schedule her next appointment.
6. Leave appropriate incentive for **Visit Two.**
7. Complete the Visit Two Encounter Form.

Chapter 7
Follow-Up Contacts & Visit Three

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CHAPTER 7

Follow-Up Contacts & Visit Three

7.1 ROSE Tidbits

FOLLOW-UP CONTACT ***(to be conducted over the remaining 11 months)***
ROSE TIDBIT CALLS: There will be two required phone calls entitled "Rose tidbit." A "Rose tidbit" is a brief call to mention a health fact that would be of interest to the participants. The health facts are topics of interest mentioned during focus groups held before the intervention was developed.

ROSE TIDBIT CALL ONE ***(Made-two months after Visit Two)***
This Tidbit Call will emphasize heart disease and provide an opportunity to administer the Staging form.

STAGED MAILER: ***(Mailed three months after Visit Two)***
Staged mailers will consist of small 5 x 7 tri-fold pamphlets that utilize messages created and matched to the participants' stages of change determined from the Stage of Change Form completed during ROSE Tidbit Call One.

ROSE TIDBIT CALL TWO: ***(Made six months after Visit Two)***
This Tidbit Call emphasizes the importance of exercise and simply provides another opportunity to check in with the participant. In addition, the Staging form will be administered again.

STAGED MAILER: ***(Mailed seven months after Visit Two)***
The second set of staged mailers will consist of cards similar to the first set. The messages will match the stages of change as determined in Tidbit Call Two.

The purpose of the Tidbit calls is to continue participant / CHE

contact between the last two intervention visits. It also provides a chance to check on the status of the participant's mammography experience/appointment. The tidbit will be shared as a means of providing information that will help to improve quality of life for the participant. Refer to Chapter 4 on handling participants without a telephone.

7.2 Call One (Made two months after Visit 2)

7.2.1 Tidbits on Heart Disease

*Heart disease is the number one killer of American women age 35 and older.

*Some of the things that place you at risk for heart disease are within your control (smoking, high cholesterol, use of alcohol, high blood pressure and physical inactivity)

*Your diet plays an important role in keeping your heart healthy. Eat more fruits and vegetables that have been steamed, micro waved in small amounts of water or fresh. Eat low fat cuts of beef, skinned chicken, and fish.

7.2.2 Staging the Participant

During the ROSE Tidbit Call One the CHE will administer the ROSE Staging Form. This form will require the CHE to ask several questions about the participant's mammography history. How the participant responds to the questions will allow the CHE to select the appropriate staging card to be mailed later (Appendix E).

At the close of the call, complete the Encounter Form (See Appendix D for additional information).

7.3 Staging Card Mailing
(First mailing - three months after Visit 2)
(Second mailing - seven months after Visit 2)

Staging is a method that is used to identify where a person is in the process of attempting to change behavior. This idea holds true whether one is adopting new behaviors, changing new ones or eliminating old behaviors. The theory uses the assumption that change for most people is a gradual process and not something that happens all at once. There are five stages of change: (See Appendix G)

7.3.1 Precontemplation: In this stage the person has no interest or intention in changing a behavior. *"I've never thought about getting a mammogram . . . "*

7.3.2 Contemplation: In this stage the person is aware that a problem exists and is thinking of changing. *"I know I need a mammogram but . . ."*

7.3.3 Action: In this stage the person has actually changed his behavior. "I've had *one mammogram and its almost time for another. "*

7.3.4 Maintenance: In this stage the person works to maintain the behavior change and to prevent relapsing. *"I've been getting mammograms every year for the past two or three years, it's one of those things I know that I have to do."*

7.3.5 Relapse: In this stage the person has failed to continue getting mammograms according to guidelines. *"I am 55 years but I've forgotten to get my mammogram the last few years. I know this is something I need to do."*

7.4 Call Two (Made six months after Visit 2)

7.4.1 Tidbits on Exercise

*Working in the garden or doing yard work is considered exercise.

*Exercise will help keep your muscles strong thus reducing your chances of injury.

*A few minutes everyday counts. For someone who is inactive, walking to the mailbox is a great way to Start.

*You are never too old to begin to exercise. Just remember to begin slowly and always stop if you begin to have any pain at all.

*Always check with your doctor prior to beginning an exercise program.

*Complete the Encounter Form after the call is completed.

7.4.2 Completing the call

After sharing the health information on exercise the CHE will once again administer the ROSE staging form. The appropriate card will be mailed approximately 4 weeks later to the participant.

7.5 Visit Three: (Approximately one and one half hour)

HOME VISIT *#3 (last five months of intervention)*
Major Goal: *To assess the participants knowledge of Breast Self Exam and fo encourage the woman fo actively participate in her health care.*

1. Review BSE
2. If the participant HAS NOT received or scheduled her mammogram the CHE will provide more barrier counseling. If the participant has received a mammogram, discuss the

experience with her.
3. Discuss future screening (physicals, Pap smears, and mammograms)
4. Taking Care of Your Body (a discussion of empowerment)
5. Explain and, complete doctor's booklet

Visit Three is scheduled during the last five months of the intervention year for the participant. This is an important visit in that it is the last and final intervention visit for the participant.

7.5.1 Reminder Calls: Two reminder call should be made prior to Visit Three.

Call One: One to two weeks prior to scheduled appointment date.

Call Two: The day before the scheduled appointment.

7.5.2 Reacquainting Yourself: Time to get reacquainted and discuss things that may have occurred since your last visit with the participant. Please do not jump into the visit.

7.5.3 Mammography Progress: Assess if the participant has gotten a mammogram since your last visit. If not, without lecturing, encourage the woman to get a mammogram. **Refer to the participant's barrier form prior to the visit.** In depth barrier counseling may be required at this visit (since it is the last). The CHE will have to provide continued counseling on the barriers that were previously noted on the barrier form. In addition, the CHE should probe further to learn whether there may be other factors influencing the participant's decision.

7.5.4 Taking Care of Yourself: This is the time to pull together all of the information that you have shared through a general discussion of taking care of yourself.

1. Ask the participant if she still has the mini breast model so that she may demonstrate BSE. If she doesn't, (or if the participant chooses) have the participant demonstrate using the Health Edco

models. While the participant is demonstrating make note of her technique. Once she completes her demonstration, walk her through the process again, being sure to correct mistakes that the participant made during her demonstration.

2. Ask the woman if she has had a recent Pap smear. A Pap smear provides the doctor the opportunity to examine a woman's cervical cells under a microscope to see if they are healthy. Even if a woman has had a hysterectomy she may still need a Pap smear. Every woman should have a Pap smear once a year.

3. Encourage the participant to begin a partnership with her doctor to take care of herself. She can do this by learning all she can about the different medical problems that she may have, ask questions so that she can gain a better understanding, go to the doctor prepared (write down your questions before the visit), keep up with doctors appointments and dates for yearly exams.

4. Go through the **ROSE** doctor's booklet page by page and assist the participant in completing it. Explain that completing and utilizing this booklet can be an important step in playing a more active role in her own health. (See Appendix G)

5. Ask the participant if she has discussed breast health with anyone since the ROSE intervention began. If the participant is willing to share, probe further. This information should be noted on the Visit Three Encounter Form.

6. As you end Visit Three with the participant be sure to thank her for allowing you to spend time with her in her home. Also, inform the participant that a ROSE interviewer will contact her to set up a time to come back to complete the following survey.

Chapter 8
Administrative Procedures

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CHAPTER 8

Administrative Procedures

8.1 Reporting Time Worked

Community Health Educators should note hours (up to 30 hours per week) worked in keeping with Wake Forest University School of Medicine time tracking procedures. As you may know, you will receive your pay checks by direct deposit every other Friday. Since your pay period is 2 weeks, you are. considered to be a biweekly employee. The following is some helpful information to keep in mind about your work hours.

8.1.1 Bubble Card Procedures

The red and white Kronos AES (Bubble) Card is to be used to submit hours to be paid which cannot be recorded by swiping an I.D. badge through a time recording station. Examples of time to be submitted using the Bubble Card would include vacation, sick or excused hours.

It is extremely important that the Card be completed correctly so that your pay will be computed accurately and on time. **The following procedure must be adhered to when completing a Bubble Card.**

1. Sign your name and record the date in **ink** at the top of the Bubble Card. Please have your supervisor sign and date the Bubble Card at the bottom in **ink.**

2. Use a number two (#2) **pencil** to fill in the Card. Do not use ink.

3. Put the Department Number (194) and the Section Number (333 for Epidemiology) at the top right corner of the card.

4. Do not make any erasures on the Card. The scanner equipment will detect erasures and read them, causing the Card to be rejected.

5. Do not fold the Card.

6. All applicable sections of the Card must be filled in completely. Therefore, all columns of each block should be completed:

   a. **Employee I.D. No.** - This must always begin with a zero (0). The remaining nine (9) digits should be your social security number.
   b. **Week Starting** - The pay week for WFUSM always begins on **SUNDAY.** Therefore, the Mon (month) and Day must be the date of the Sunday for the pay week.
   c. **CAT NO.** - Category number for the type of hours being reported. A list of the valid categories are listed below:
      01 Regular
      32 Vacation
      33 Sick
      34 Excused
   d. **NO. OF HOURS** - Number of hours being reported. Time should be recorded in hours and tenths (i.e., eight hours would be recorded at 08.00, two hours and twenty-six minutes as 02.40).
   e. **NEVER RECORD HOLIDAY TIME ON A BUBBLE CARD**

In the event a bubble card is turned in late, you will need to write a note to your supervisor explaining why the bubble card is late. We will then forward the bubble card to Payroll.

Please check your bubble card(s) carefully to make sure all bubbles have been colored in and that the week starting is correct. Time does not allow us to correct bubble cards. In the event your bubble card is filled out incorrectly, **it will be sent back to you for correction. This may mean that you will not get paid on time.**

In the event you should have any questions, please feel free to call Alma at **(336)716-3066**, Doris at **(336)716- 5131**, or Cathy at **(336)716-6717.** If we are unavailable, please leave a message.

8.2 Field Reporting and Communications

General **ROSE** administrative policy for field staff is presented in this chapter of this manual. These procedures will normally apply to all work performed for Wake Forest University School of Medicine on the **ROSE** Project. Please review this chapter carefully before going further with this manual.

As a **ROSE** Community Health Educator, you will report to Janice Strickland, the local Assistant Project Manager, on a regular basis and the Program Coordinator, Alma Wilson, on a weekly basis. You will be provided with a regular schedule for these weekly appointments. You should bring your PET, weekly report form and all your intervention materials **(work in progress as well as completed work) to these weekly meetings.**

During these weekly meetings you and your supervisor will review:

(1) your production during the reporting week
(2) your planned activities and schedule for the current week
(3) your job performance (efficiency, and quality of completed work)
(4) any questions or concerns she may have about your Production, Expense and Time Report Form (PET), and
(5) any other topics relevant to your assignment. You should also be prepared to discuss during the weekly meeting any questions or problems that you may have.

If you encounter problems or have questions during the week that need immediate attention, make a special call to the Assistant Project Manager, **Janice Strickland, at (910) 739-9511.** You may also call your supervisor if she is not available. Do not wait until the next time you see her. If you need advice or assistance and your supervisor cannot be reached, call **Cathy Tatum at 336-716-6717 or Ginger Graham at 336-716-9178.**

ROSEN/WFUSM recognizes the need for full and clear communication between the community health educators and office staff. Community Health Educators will be provided with names and telephone numbers of all personnel with whom they may need to communicate during fieldwork for a study. In addition you will be expected to attend any **ROSE** field staff meetings scheduled by your supervisor.

8.3 Production, Expense, and Time Reporting

8.3.1 Allowable Charges

Time and expense charges must be allowable under **ROSE/WFUSM** policy if you are to be reimbursed. Allowable charges are discussed in this section. Please review this before beginning your **ROSE** assignment in order to avoid any misunderstanding.

8.3.2 Completing the Report

The Production, Expense and Time **(PET)** Report Form provides you, your supervisor and **ROSE** office staff with a detailed summary of tasks completed during the one-week period covered by the report and the time spent and expenses incurred in completing these tasks. Step-by-step instructions for completing this form are provided below. An example of a properly completed PET Report Form is shown in the Appendix E. Please refer to these instructions and the example as you are completing your reports to be sure you are making all required entries correctly.

Community Health Educator ID #--Enter your identification number (the last four digits of your social security number).

Week Beginning --Enter date (month, day, and year) of the Sunday on which the reporting period begins. Each reporting period runs for 7 days, from Sunday through the following Saturday. A report must be prepared and submitted for every one-week period during the entire project period. If you did not work during a reporting period, write “DID NOT WORK” across the front of the form. Also, complete your name, signature and ID#.

Section A (Total Hours Worked)--Enter the total number of hours worked for each day of the week-Sunday through Saturday. Time reported in columns E-1 through E-5 should equal column A for each day worked.

Section B & C (Production)--Enter the number of encounter forms completed on the appropriate lines in column B. In column C, enter the number of attempted interviews.

Section D (Day of Week)--This section identifies the 7 days in the one week reporting period. For each day you work, the

appropriate entries should be made in the columns to the right and left on the line for that day.

Section E (Hours Worked) -- For each day that you work, record in Column A. Partial hours should be expressed in decimal form rather than as a fraction (e.g., 5.5 hours instead of 5½ hours). Time should be rounded to the one half (.5) hour Then allocate the total time worked across column E1 through column E5 as appropriate, again using decimals rather than fractions to express partial hours. These "hours worked" categories are defined as Follows:

(1) Interviewing/Educating - Record the time spent conducting educational training sessions in homes or phone contacts with participants.

(2) Contacting and Locating - record the time spent traveling to and from sample members homes, to the **ROSE** Office, etc.(Instructions for completing the **ROSE** Weekly Travel Log follow).

(3) Editing - Record the time spent editing completed work such as encounter forms, contamination logs, etc. (including completion of all other forms except PET).

(4) Conference/Meeting - Record time spent making field status reports and conferring with your supervisor, and **ROSE** staff meetings.

(5) Other - Use this column to record time spent preparing for field work, completing the PET, and performing other allowable project activities. Note that you must describe "other" activities on the PET Comments Form.

Section F (Expenses)--Record the number of miles driven on project business. Make sure that you have entered the corresponding travel time under contacting and locating (column E-2).

Totals--Total all columns (columns A and column E1-E5), then check your calculations! Remember to express partial hours in Section E in decimal form rather than as fractions.

Interviewer/CHE Identification Section--Complete this section by recording your name **(please print)**, date, complete mailing address, and telephone number. Then sign and date the form.

The PET Form will only reflect the time worked and not any projected hours.

8.3.3 Equipment and Supplies

As previously noted, CHEs will receive an initial assignment with all necessary equipment and supplies at the training session. These materials include encounter forms, contamination logs and other data collection forms designed for health education, reporting forms, necessary office supply items and any other materials needed for the study. You will also be told at the training session how supplies are to be obtained on a regular basis. CHE's should conduct a weekly inventory to insure against running out of needed supplies and not being able to complete scheduled work. Any unused supplies you have when you have completed fieldwork for **ROSE** must be returned to your supervisor.

Remember that all materials provided are the property of **ROSE/WFUSM. All forms and information are highly confidential in nature (blank as well as completed) and special care should be taken with them. CHE's are not to allow nonrespondents or potential respondents to review study materials, nor are they to allow anyone to have or copy any study materials.**

Instructions for disposition of remaining equipment and supplies will be provided before work on the survey is complete.

8.3.4 Travel

Community Health Educators will be reimbursed for travel expenses associated with work on the **ROSE** Project. When traveling in the field for **ROSE**, the first thing the employee must do is record the starting mileage and purpose of the trip. When returning from the interview site, the employee must record the ending mileage and total mileage for the trip. A travel log form is provided for that purpose. **Complete and turn in a Weekly Travel Log each**

week. This should reflect only travel to complete your ROSE assignments unless approved by the Project Manager.

Procedures for Completing the Weekly Travel Log -

The Weekly Travel Log should be completed by filling in each space as follows:

Name:	Name of Community Health Educator completing form.
Soc. Sec. **#:**	Social Security number of Community Health Educator completing form.
Date:	Date of trip.
Destination:	Site to which traveled.
Miles:	Number of miles traveled during trip.
Reason for Trip:	Brief explanation of why CHE traveled to site
Total Miles:	Sum total of miles traveled

APPENDICES

Appendix A:	Project Summary/Description
Appendix B:	Community Advisory Board and Medical Advisory Board
Appendix C:	ROSE Staff List
Appendix D:	Breast Educational Materials
Appendix E:	CHE Forms
Appendix F:	CHE ID Letter
Appendix G:	Intervention Materials

APPENDIX A

Project Summary/Description

Rose

Robeson County Outreach Screening and Education Project

Robeson Health Care Corporation
&
The Wake Forest University School of Medicine

The Robeson County Outreach, Screening and Education (ROSE) Project is a four year project funded by the National Cancer Institute of the National Institutes of Health. It is being conducted by researchers from the Wake Forest University School of Medicine and Robeson Health Care Corporation (RHCC). The goal of this project is to increase early detection of breast cancer by increasing the proportion of low income rural women age 40 and older who receive clinical breast exams and mammograms at appropriate intervals and return for follow-up care when necessary. This project will be conducted in Robeson County, NC. This county has a population comprised of three principal ethnic groups of approximately equal size: whites, African Americans and Native Americans. An individualized health education program will be developed and compared to a brochure and letter in a randomized trial design among 1000 women aged 40 and older who are patients of Robeson Health Care Corporation, the principal provider of health care for this population. An additional aim of the project relates to assuring adequate follow-up among women with abnormal tests results.

Specific aims of the project are:

* to identify barriers to obtaining regular clinical breast exams and mammograms,
* to develop a health education program to improve knowledge and practices,
* to address the identified structural and personal barriers to behavior change and
* to motivate women in the target population to obtain clinical breast exams and mammograms.

We will also evaluate, through use of a randomized design, the impact of the health education program compared to a brochure plus physician letter on the proportion of women obtaining regular clinical breast exams and mammography. The project will explore the differential effects of the health education intervention to enhance participation in breast cancer screening among rural white, African American and Native American women, groups that are traditionally underserved by cancer control efforts and services. Factors will be identified that impede follow-up and treatment of abnormal or suspicious findings with a goal of improving adherence with recommendations for follow-up of abnormalities detected among women in the study.

Eligible participants will include women, age 40 and older who are patients of Robeson Health Care Corporation and reside in Robeson County. All participants will receive their usual medical care from RHCC. Data will be collected by in person interview with verification of mammography and CBE by medical record review by RHCC staff. A total of 1000 women will be recruited and randomized into either the intervention group or the brochure group. Follow-up will be staggered over a 1 year period for each participant.

If this program is successful in improving breast cancer screening practices among this population of tri-racial women, lay health educators from a variety of community organizations can be trained and supervised by health departments to deliver similar programs to rural women.

Electra Paskett, Ph.D.	Principal Investigator	Dennis Stuart, M.D.	Co-Investigator
Robert Michielutte, Ph.D.	Co-Investigator	Ronald Bell, Ph.D.	Co-Investigator
Ralph D'Agostino, Jr., Ph.D.	Co-Investigator	Alma Wilson, M.S.	Program Coordinator
Cathy Tatum, M.A.	Project Manager	Doris Mack	Assoc. Project Manager
Janice Strickland	Assist. Project Manager		

APPENDIX B

Community Advisory Board and Medical Advisory Board

ROSE

Robeson County Outreach Screening and Education Project

Community Advisory Board

Name	Affiliation
Angela Conner	American Cancer Society
Mary Monroe	Southeast Regional Medical Center CAP Program
Clarissa Woodman	Southeast Regional Medical Center CAP Program
Shelby Foy	Lumberton Housing Authority
Carlena Platt	Happy Hill Word of Del. Fellowship Church
Doris McDonald	Robeson County Health Department-BCCCP Program
Louise Lassiter	Community
Betty Thomhill	Community
Barbara Barton	Community
Betty Sampson	Community
Brenda Brooks	Community
Karen Kay	Community
Camma Morgan	Community
Terri Oxendine	Community

****

Medical Advisory Board

Name	Affiliation
Dermis Stuart	Robeson Health Care Corporation
Bob Foster	Robeson Health Care Corporation
Connie Locklear-Jones	Robeson Health Care Corporation
Paulette Collins	Southeast Regional Medical Center
Mary Black	Southeast Regional Medical Center - Wellness Director
Patricia McCrae	Southeast Regional Medical Center - Nurse
Vicki Bell	Radiology Technician
Eva Meekins	UNC - Pembroke
Annie Hayes	UNC - Pembroke
Terri Nicholson	Lumberton Radiological Associates
Jean-Claude Martin	Robeson County Health Department
Arnette Melvin	AVON Nurse
Cora Bullard	Robeson Health Care Corporation - Nursing Coordinator

APPENDIX C

ROSE Staff List

ROSE Telephone List
Wake Forest University School of Medicine

Electra Paskett, Ph.D.
Principal Investigator
Wake Forest University School of Medicine
Department of Public Health Sciences
Medical Center Boulevard
Winston-Salem, NC 27157
Telephone: (336) 716-6946
Fax: (336) 716-5431
E-Mail: epaskett@rc.phs.wfubmc.edu

Robert Michielutte, Ph.D.
Co-Investigator
Wake Forest University School of Medicine
Dept. of Family and Community Medicine
Medical Center Boulevard
Winston-Salem, NC 27157
Telephone: (336) 716-2241
Fax: (336) 716-9126
E-Mail: bmichiel@wfubmc.edu

Ronny Bell, Ph.D.
Co-Investigator
Wake Forest University School of Medicine
Department of Public Health Sciences
Medical Center Boulevard
Winston-Salem, NC 27157
Telephone: (336) 716-9736
Fax: (336) 716-5425
E-Mail: rbell@rc.phs.wfubmc.edu

Ralph D'Agostino, Jr., Ph.D.
Co-Investigator
Wake Forest University School of Medicine
Department of Public Health Sciences
Medical Center Boulevard
Winston-Salem, NC 27157
Telephone: (336) 716-9410
Fax: (336) 716-5425
E-Mail: rdagosti@rc.phs.wfubmc.edu

Brent Shelton, M.S.
Biostatistician
Wake Forest University School of Medicine
Department of Public Health Sciences
Medical Center Boulevard
Winston-Salem, NC 27157
Telephone: (336) 716-6019
Fax: (336) 716-5425
E-Mail: bshelton@rc.phs.wfubmc.edu

Cathy Tatum, M.A.
Research Associate
Project Manager
Wake Forest University School of Medicine
Department of Public Health Sciences
Medical Center Boulevard
Winston-Salem, NC 27157
Telephone: (336) 716-6717
Fax: (336) 716-3028
E-Mail: ctatum@rc.phs.wfubmc.edu

Doris Mack
Associate Project Manager
Wake Forest University School of Medicine
Department of Public Health Sciences
Medical Center Boulevard
Winston-Salem, NC 27157
Telephone: (336) 716-5131
Fax: (336) 716-3028
E-Mail: dmack@rc.phs.wfubmc.edu

Alma Wilson, M.S.
Program Coordinator
Wake Forest University School of Medicine
Department of Public Health Sciences
Medical Center Boulevard
Winston-Salem, NC 27157
Telephone: (336) 716-3066
Fax: (336) 716-3028
E-Mail: awilson@rc.phs.wfubmc.edu

Ginger Graham
Administrative Secretary
Wake Forest University School of Medicine
Department of Public Health Sciences
Medical Center Boulevard
Winston-Salem, NC 27157
Telephone: (336) 716-9178
Fax: (336) 716-5431
E-Mail: ggraham@rc.phs.wfubmc.edu

ROSE Telephone List
Robeson Health Care Corporation

Dennis Stuart, M.D.
VP of Medical Activities/Chief Medical Officer
Robeson Health Care Corporation
1212 S. Walnut Street
Fairmont, NC 28340
Telephone: (910) 628-6711
Fax: (910) 628-5735

Janice Strickland
Assistant Project Manager - ROSE
Robeson Health Care Corporation
901-A N. Chestnut Street
Lumberton, NC 28358
Telephone: (910) 739-9511
Fax: (910) 739-9577
E-Mail: roseproject@carolina.net
Pager: 1-888-310-4945

Jinnie Lowery
President/CEO
Robeson Health Care Corporation
1211 S. Walnut Street
Fairmont, NC 28340
Telephone: (910) 628-5200
Fax: (910) 628-6205

Paul F. Kittinger, Jr.
VP of Operations/COO
Robeson Health Care Corporation
1211 S. Walnut Street
Fairmont, NC 28340
Telephone: (910) 628-5200
Fax: (910) 628-6205

Bob Foster
Director of Quality Management
Robeson Health Care Corporation
1211 S. Walnut Street
Fairmont, NC 28340
Telephone: (910) 628-5200
Fax: (910) 628-6205

Eleanor Chebahtah
Budget Officer
Robeson Health Care Corporation
1211 S. Walnut Street
Fairmont, NC 28340
Telephone: (910) 628-5200
Fax: (910) 628-6205

Mary Thomas-Locklear
Director of Human Resources
Robeson Health Care Corporation
1211 S. Walnut Street
Fairmont, NC 28340
Telephone: (910) 628-5200
Fax: (910) 628-6205

Chuck Gavazzi
Human Resources Manager
Robeson Health Care Corporation
1211 S. Walnut Street
Fairmont, NC 28340
Telephone: (910) 628-5200
Fax: (910) 628-6205

APPENDIX D

Breast Educational Materials

A Woman's Guide To Breast Health

REPRODUCIBLE RESOURCES
FOR EDUCATION, TRAINING AND AWARENESS

PARLAY INTERNATIONAL

A Woman's Guide To Breast Health...

The Facts about Breast Cancer

Breast cancer is the most common cancer occurring in women. About one out of every ten women will get breast cancer and many thousands die each year from this disease. If detected early, before it affects the lymph nodes, the chances of surviving breast cancer are nearly 90 percent.

What Is Breast Cancer?

The word "cancer' is used by scientists to describe hundreds of diseases characterized by unrestrained cell growth. Breast cancer begins in the breast tissue and, if undetected and untreated, can invade other tissue and lead to death. No one knows the exact causes of breast cancer. Medical research is seeking to discover the causes of this disease, as well as cures.

Who's at Risk?

Women who have close relatives with breast cancer, like mothers or sisters, have a greater chance than others for developing the disease. Some studies show that diets high in animal fats or not having children before age 30 may be associated with the development of breast cancer.

How Is Breast Cancer Treated?

A biopsy, removal of a very tiny bit of breast tissue, must be done to diagnose breast cancer. Many altematives exist today for treatment of breast cancer; these depend on the type of cancer and how early it is detected.

When to See Your Doctor

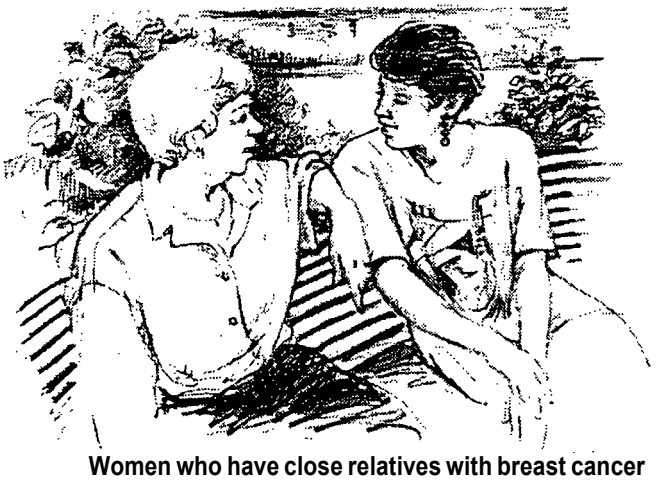
When you notice any change in your breast, see your doctor immediately. The longer you wait, the greater chance the disease could spread to other parts of your body.

How to Avoid Breast Cancer

Although scientists are learning more and more about breast cancer, there is still no sure-fire way to prevent it. But it can be a curable disease if it is found early. There are three important things you can do to protect yourself from breast cancer: breast self-examinations, regular checkups by a healthcare professional, and a baseline mammogram if you are over 35.

What Are The Signs of Breast Cancer?

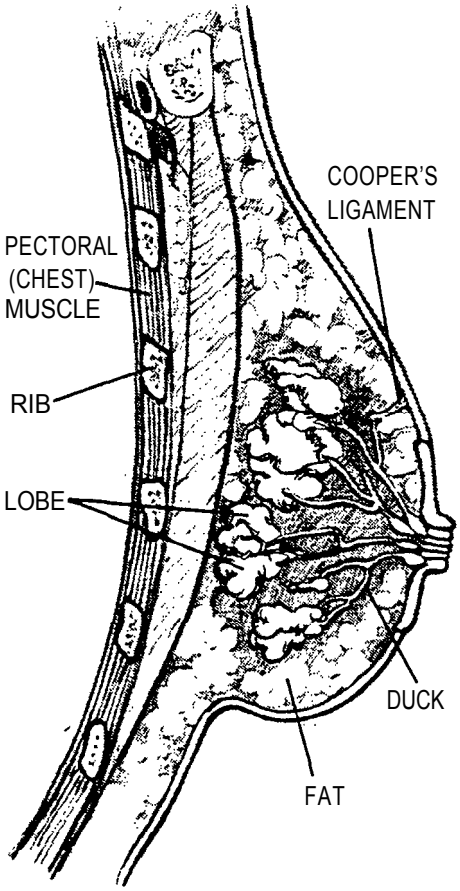
- Lump or thickening in the breast
- Bleeding or discharge from the nipple
- Puckering or "dimpling" of the breast skin
- A change in the shape of the breast
- A pulling back (retraction) or scale-like appearance of the nipple
- Reddish, inflamed breast tissue

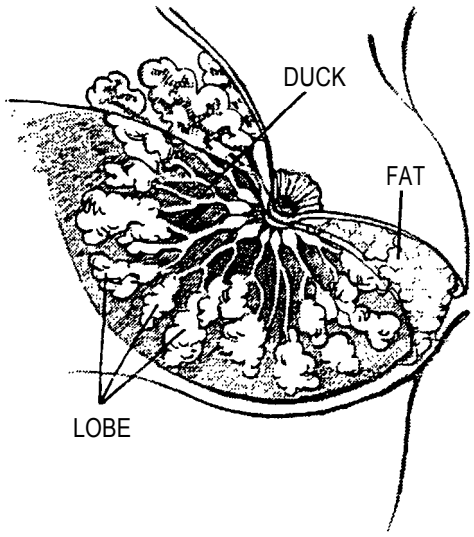


Women who have close relatives with breast cancer have a greater chance for developing the disease.

A Woman's Guide To Breast Health...

The Facts about Breast Cancer





What Is Normal?

Many of us may not examine our breasts every month because we are not sure what to feel or look for. If we can understand how a normal breast looks and feels, we can then detect a lump in a breast that sometimes feels plain "lumpy."

No two breasts are exactly alike, not even on the same person. Most breasts appear as mounds on the chest wall and are completely smooth. The total breast actually includes tissue that extends from under the armpit, from the collarbone downward, and from the back toward the chest.

Inside the Breast

Inside the breast are fibrous tissue, fatty tissue, and mammary glands that produce milk. The mammary glands form clusters throughout the breast and empty into ducts (tubes) leading to the nipples. Fatty tissue gives the breast its shape and softness. The fibrous tissue also gives the breast shape and helps support the breast.

How the Breast Provides Milk

After the birth of a Child, a woman's breasts are ready to give milk. The mammary glands, responding to hormones from pregnancy, have greatly enlarged and now produce the milk that travels through ducts and is stored in the ampulla, just behind the nipple. The sucking of the baby, as well as its cry, helps to release the milk stored in the ampulla of the breast.

How Your Breast Changes

...During Your Menstrual Cycle

The female hormones, estrogen and progesterone, cause the breasts to keep fluid and swell during the week before menstruation begins. The hormone changes of the menstrual cycle can lead to the formation of tender lumps during this time, but they disappear during the week after the end of the menstrual period.

...During Pregnancy And Lactation

During pregnancy, all the structures in the breasts prepare for the manufacture of milk, which causes the breasts to greatly enlarge. The breasts will return to a smaller size once pregnancy and breastfeeding end.

...Over Time

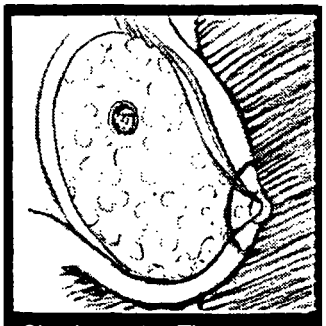
As a woman ages, her breasts change dramatically, growing at puberty and then shrinking at menopause. Because the breast contains fatty deposits, its size can increase or decrease depending on changes in a woman's weight. If you perform breast self-examination every month, you will be aware of the first signs of any changes in your breast.

A Woman's Guide To Breast Health...

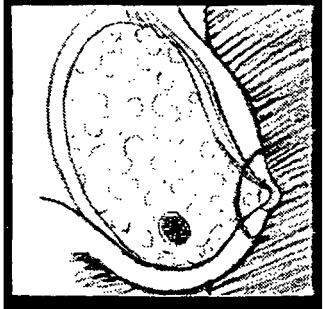
"Fibroids" and Other Benign Breast Changes

Fibrocystic Changes—A Common Problem

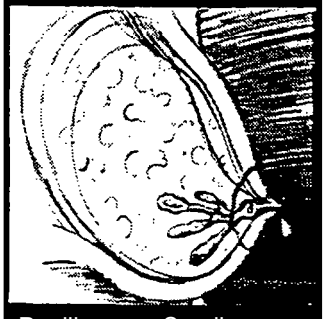
A change, thickening or a swelling in the breast does not always signal breast cancer. Most breast lumps are "benign" (not cancerous) and are not serious health problems. One kind of breast lump is the result of fibroid cystic changes (also called fibrocystic disease, cystic breast disease or mammary dysplasia).



Simple cysts: These consist of fluid-filled sacs.



Fibroadenoma: A single, solid tumor made up of fibrous and glandular tissue.



Papillomas: Small, wartlike tissue that grows in the lining of the mammary duct.

What Are Fibrocystic Changes?

Fibrocystic changes are the most common cause of breast lumps in'women from 35 to 50 and do not really qualify as a "disease." They are thought to be the body's overreaction to normal hormonal changes in a woman's monthly cycle. This reaction to the ups and downs of natural hormones causes many pockets of fluid to form. These fluid pockets are called sacs or cysts and they can lead to an increase in fibrous, rubbery tissue in the breast. Lump size and breast tendemess usually increase the week before the menstrual period and decrease within the week after menstruation. For most women, lumps stop forming after menopause.

Kinds of Cysts

Simple cysts: These consist of many fluid-filled sacs. No increase in fibrous tissue occurs. Breast tendemess and lump size change with the menstrual cycle.

Fibroadenoma: A single, solid tumor made up of fibrous and glandular tissue. Women between 18 and 35 commonly develop these tumors. Premenstrual tendemess can occur in the breast and lump.

Papillomas: Small, wartlike tissue that grows in the lining of the mammary duct. These usually locate near the nipple, sometimes causing a bloody or clear discharge from the nipple itself.

Signs Of Fibrocystic Changes

- Lumpy feeling in the breast
- Breast pain
- Premenstrual breast discomfort
- No symptoms at all

Helpful Hints

You can try these hints to relieve the swelling and discomfort of fibrocystic lumps:

- Keep away from coffee (both caffeinated and decaffeinated), teas, colas, soft drinks, chocolate, and cocoa.
- Reduce the amount of Salt in your diet, especially during the last half of your menstrual cycle.
- Tell you doctor about any problems as soon as you discover them.

A Woman's Guide To Breast Health...

"Fibroids" and Other Benign Breast Changes

Have a yearly professional breast examination.

Benign Breast Conditions

Most women will develop a benign breast lump at least once in their life. While fibroid cysts are the most common type, breast lumps and swelling may also be caused by simple cysts, mastitis, or lipomas.

Simple Cysts

Simple cysts are either single or multiple fluid-filled sacs. Unlike fibroid cysts, these lumps are not accompanied by increases in fibrous tissue in the breast, but their tenderness and changes in size can rise and fall with the menstrual cycle. The cause may be an injury or a trauma to the breast, resulting in an accumulation of blood (a hematoma) or the breakdown of fatty tissue (fat necrosis); Such an injury does not cause cancer but may be painful. You may wish to discuss breast trauma with your doctor so he or she can follow its healing.

Mastitis and Its Treatment

Mastitis is an infection in the breast tissue. This occurs when bacteria get into the mammary ducts through the Apple. Mastitis often results during breastfeeding. Pockets of infection then can be felt as tender lumps. Mastitis is easily treated with antibiotics and breastfeeding can continue during treatment. Mastitis is not related to breast cancer.

What Is a Lipoma?

A lipoma in the breast is a soft lump made up of fatty tissue. A lipoma can result from a bump or a bruise on the breast and may form many years after the actual trauma. Lipomas do not appear to increase the risk of breast cancer.

Breast Biopsies

A biopsy means the removal of a tiny piece of breast tissue from a specific location so it can be checked under a microscope. Because the majority of breast lumps are benign, most doctors recommend a breast biopsy only to ensure that the lump or change in your breast is not cancer. The tissue removed during a breast biopsy is usually frozen and then sliced into very thin sections. A pathologist, a medical doctor specially trained in identifying disease in cells, looks at the slice of breast tissue under a microscope. Only with a biopsy can a doctor make a totally accurate diagnosis of the problem.

Regular Checkups

Your general health depends on regular breast checkups:

- Leam how to check for changes in your breasts and examine them each month. If you menstruate, the best time is one week after the start of your period.
- Have yearly checkups that include a breast examina: tion by a healthcare professional.
- Get mammograms according to your age and the general status of your health.

Special Note

Althoughfibrocystic changes are not cancerous or serious, you should tell you doctor about *any* breast problem right away.

A Woman's Guide To Breast Health...

Detecting Breast Changes

Breast Self-Examination

Breast care is a very important part of a woman's healthcare regimen. Checking for changes in the way her breasts look and feel should become a routine task for any woman. The breast self-examination is not difficult or time-consuming: it takes only a few minutes to leam and to do each month.

Changes in the Breast

Breast "changes" are any changes from what is normal for you. For example, many women have "grainy" or "lumpy" breast tissue but their breasts do not actually have lumps. Other women may have a light pearly colored nipple discharge that is usual for them. The best way to get to know what is normal for your breasts is to perform the breast self-examination every month.

When To Do the Breast Self-Exam

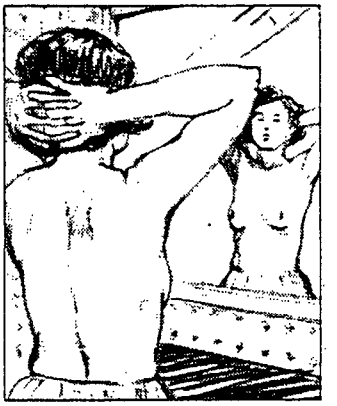
The hormonal changes of the menstrual cycle can cause differences in the way your breasts feel throughout the month. So it is important that you check your breasts at the same time each month. If you menstruate, it is best to perform the breast self-examination one week after the start of your period.

Routine Checkups

In addition to the monthly breast self-exam, you need regular breast examinations by a healthcare professional and should follow your doctor's recommendations about mammography (X-ray checkup of the breast).

HOW TO DO THE BREAST SELF-EXAM

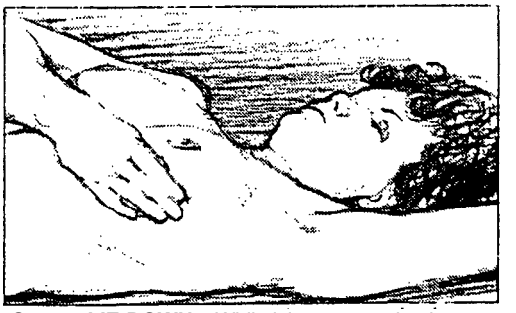
Step 1. LOOK —Sanding in front of a mirror, look at how your breasts appear while you hold your arms at your side. If you notice dimpling or skin or nipple changes, call your doctor.



Step 2. LOOK—While in front of the mirror, look at your breasts while you raise your arms to behind your head. If you notice dimpling or skin or nipple changes, call your doctor.

Step 3. LOOK—Still in front of the mirror, place your arms on your hips. If you notice dimpling or skin or nipple changes, call your doctor.

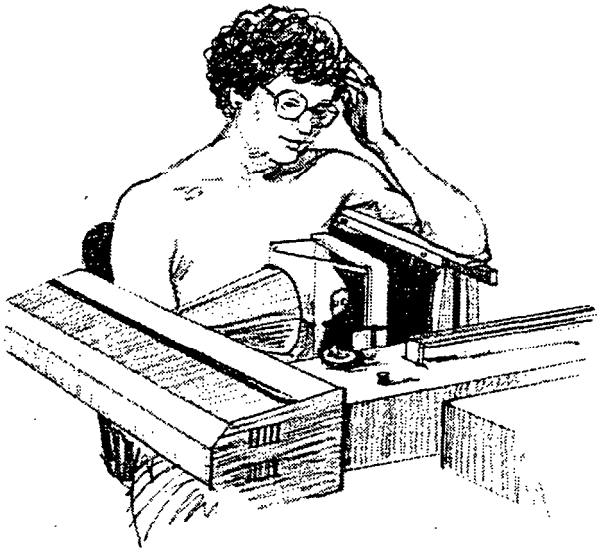
Step 4. CHECK THE NIPPLES —Using your thumb **and forefinger, squeeze your nipple as shown.** Many women have a whitish-colored discharge, but if you notice a pus-like discharge or rust-colored fluid comes from a nipple, call your doctor.



Step 5. LIE DOWN—While lying on your back, raise one arm above your head. Examine the. breast on that side, thinking of it as divided into parallel "strips." Check each strip with the pads of your fingertips, using small, circular movements. Change the pressure as you feel for changes, such as grains or lumps, throughout the breast. If you feel any changes, call your doctor.

A Woman's Guide To Breast Health...

Detecting Breast Changes



Routine Mammography

It is comforting to know that most breast lumps are not cancerous. For the small percentage that are, early detection greatly increases the chances of successful treatment and cure. The best way to detect breast cancer before it becomes life-threatening is to practice monthly breast self-examination, have yearly checkups by a healthcare professional, and have periodic mammograms.

Mammography

Mammography is a breast-screening examination that uses low doses of X-rays to check the inner tissue of the breast. The average mammogram gives off less radiation than most dental X-rays. Mammograms can often detect breast lumps before they can be felt. This is very important because breast cancer found in its early stages often can be cured.

What Does a Mammogram Show?

A mammogram shows the similarity between the woman's two breasts. The X-ray picture also detects lumps and calcium-like deposits in the breast tissue. This may help the doctor decide if a lump is benign (not cancerous) or malignant (cancerous). If the woman has had one or more mammograms, the doctor compares the most recent X-ray with her other mammograms to check for any changes in the breasts. Doctors like mammography because it can sometimes detect breast cancer before it can be felt during a manual examination and because it is considered to be about 85 percent accurate in diagnosing a breast lump.

What Happens During a Mammogram?

Depending on the kind of machine used, you may be asked to sit, stand, or lie down during the mammogram. A plastic sheet, sponge or balloon may be used to press the breast for the X-ray picture. Several X-rays are taken of each breast. A radiologist, a doctor trained to study X-rays, checks the mammogram.

Who Should Have Mammography?

Doctors' opinions vary, but many doctors follow the American Cancer Society's recommendation for a baseline (or first) mammogram for all women between the ages of 35 and 40 years. After this time, one mammogram every two years is suggested until the age of 50. After age 50, women should have a mammogram of the breasts once each year. Doctors have leamed that a normal mammogram does not always mean the lump is benign. Therefore, a biopsy of the breast should be done to check a suspicious lump.

The Safety of Mammography

The benefits of early cancer diagnosis far outweigh the risks caused by the use of X-rays. Differing opinions over the safety of mammography are only related to the regular, yearly test in women with healthy breasts and no signs of breast cancer.

A Woman's Guide To Breast Health...

Diagnosing Breast Disease

Needle Aspiration

Regular physical checkups and your own self-examination of your breasts are important to your health. During your routine visit to your doctor, always ask any questions you may have about your breasts or any changes you have noticed since your last checkup. If you should find a lump, tell your doctor immediately. Do not become frightened or panic. Most breast lumps are not cancerous.

If Your Doctor Recommends a Needle Aspiration

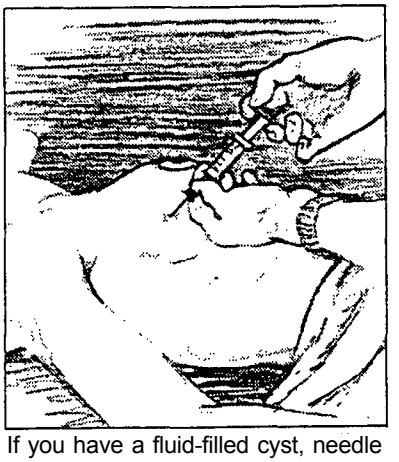
If your doctor decides that a lump on your breast seems suspicious or questionable, he or she may decide to study it further by means of medical tests. One such test involves the aspiration of the lumpy area. An aspiration biopsy may be performed if your doctor feels a lump in your breast that seems to be filled with fluid. This kind of lump is known as a cyst. Usually benign, cysts can be drained by using a common syringe and needle to draw out the fluid. Needle aspiration may also be performed on a solid breast lunp or thick area to withdraw a few cells for later study under a microscope in a laboratory.

The Needle Aspiration Procedure

The needle aspiration procedure is usually done in the doctor's Office under local anesthesia. The doctor rubs the section of the breast with an antiseptic and then numbs the area around the fluid-filled cyst. When the anesthesia has taken effect, the doctor inserts a thin hypodermic needle attached to a syringe into the cyst and draws out the fluid. The doctor may send the fluid to a laboratory for further testing and observation. The fluid in the cyst can vary in color but it should not be red; that is, it should not have blood cells in it. If the fluid appears suspicious or if the breast lump does not decrease right away, the fluid will be sent to a cytology laboratory, where the cells will be checked under a microscope.

What Is Learned

After the fluid has been removed from the cyst, you and your doctor will continue to watch the affected breast area. If the lump disappears after the needle aspiration procedure, you may need to continue regular Office examinations for a period of time to be sure that the lump does not grow back. If the cells in the fluid show cancer, the needle aspiration is said to be "positive." If the cell sample is "negative," the lump may still be cancerous. A tissue biopsy is the next step for a solid lump that has shown a negative needle aspiration result.



If you have a fluid-filled cyst, needle aspiration may be used.

One Last Note

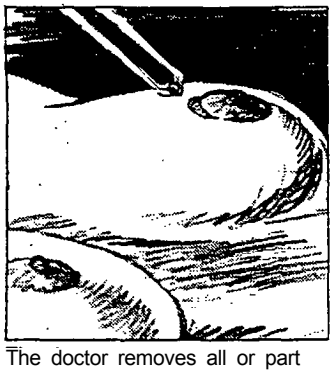
Needle aspirations are usually used for fluid-filled cysts rather than solid lumps. They are quick and generally inexpensive. Best of all, a needle aspiration leaves no scar.

A Woman's Guide To Breast Health...

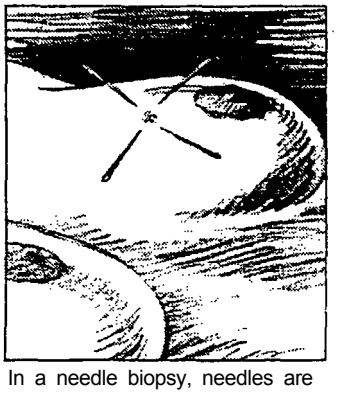
Diagnosing Breast Disease

Surgical and Needle Biopsy

In a surgical biopsy, an incision is made as near to the nipple as possible.



The doctor removes all or part of the lump and sends it to the lab for study.



In a needle biopsy, needles are used to mark the suspicious area for the surgeon.

Your doctor may be uncertain about the breast lump detected by your self-examination, the Office physical examination or X-rays. He or she may recommend a surgical or needle biopsy of the breast lump that involves the removal of a small bit of tissue from the lump. The lump tissue is sent directly to a laboratory for study to determine if it is cancerous or benign. Most breast lumps are benign and require no further surgery. But if the breast lump is diagnosed as malignant or cancerous, other medical treatments must start as soon as possible for the best health outcome.

What Is a Surgical Biopsy?

In a surgical biopsy, either all or part of the breast lump is removed. An excisional biopsy means that the whole lump and sometimes the area surrounding it is cut out. An incisional biopsy includes the removal of part of the suspicious lunp. If the lump appears on the surface of the breast, local anesthesia may be preferred and the procedure done in the doctor's office. For deep breast lumps, hospitalization and general anesthesia may be best for the patient. The surgical biopsy may require stitches to close the incision. The lump tissue then goes to the cytology laboratory for study. Most women recover from a surgical biopsy in a day or two. Heavy exercise that can shake the breast, such as jogging, should be stopped—usually for a few weeks.

What Is a Needle Biopsy?

If the breast lump has been located by mammography rather man by feeling, a needle biopsy may be recommended. The radiologist who has studied the mammogram X-ray marks the suspicious section of the breast with one or more needles. Then the surgeon cuts out that marked area of the breast. Before starting a needle biopsy, an antiseptic solution and possibly a local anesthetic are applied to the breast area. The correct needle placement is viewed on another mammogram before the biopsy continues. If the lump or questionable area hes deep within the breast, hospitalization and a general anesthetic may be recommended. After the needle biopsy, the excised tissue is X-rayed to make sure it contains all the marked area. It is then sent to the cytology laboratory for study and analysis.

When a Breast Biopsy Is Recommended

A breast biopsy is usually recommended when the doctor has doubts or concems about a persistent lump, nipple discharge or skin puckering on the breast. A biopsy of the breast may also aid in understanding abnormal findings from X-rays.

A pathologist, a doctor trained to classify cells and tissues for disease conditions, "stages" the lump tissue. Staging means ranking the amount of disease seen in this particular tissue sample. Staging helps your doctor choose the best treatment for your individual condition.

A Woman's Guide To Breast Health...

Treating Breast Cancer

When a woman learns she has breast cancer, there is one important thing for her to remember: hundreds of thousands of people have survived cancer. Her chances for survival are best if her cancer has been diagnosed early, but even if her disease is advanced survival is still possible. She will need emotional strength, a never-say-die attitude, and a willingness to explore options. If you have been diagnosed with breast cancer, learn as much as you can about the disease and the variety of treatments available.

Today's Options

New treatments for breast cancer are being developed every year. In fact, new discoveries are being made so quickly that doctors are challenged to keep pace with the developments. In the past, most doctors chose radical mastectomy (also known as the Halsted radical mastectomy) to treat breast cancer. This involved the complete removal of the breast tissue as well as the muscles under the breasts on the chest wall and the lymph glands or nodes under the woman's arms to make sure cancer cells had not invaded these areas.

Medical advances have made it possible for a woman and her doctor to select a course of treatment from a variety of surgical procedures, radiation therapy and chemotherapy. Your doctor may discuss these options with you:

Modified Radical Mastectomy

The modified radical mastectomy, or total mastectomy, is a common surgical procedure for breast cancer. With this surgery the breast as well as the lymph nodes under the arm are removed, but the chest muscles lying under the breast tissue are not. Chemotherapy may be prescribed as well.

Simple Mastectomy

If laboratory tests and physical examination show the cancer to be located in the breasts only, the doctor may recommend a simple mastectomy. In this surgery the breast is removed but the chest muscles and the lymph nodes under the arms are not.

Partial Mastectomy

In a partial mastectomy, only the tumor and a specific area of tissue around the tumor are removed. In order to determine whether the cancer has spread into the underarm lymph nodes, most of the nodes are also taken out. Following a partial mastectomy, chemotherapy may be prescribed.

Lumpectomy

A woman whose cancer has been diagnosed early may have a lumpectomy, a less disfiguring procedure in which only the tumor is removed; the rest of the breast is left intact. In a recent study of women treated for early breast cancer, investigators found that survival among women who had lumpectomies was the same as that among women who had the entire breast removed. In fact, lumpectomy followed by radiation treatment of the breast decreased the likelihood of the tumor's recurrence.

Life After Surgery

Healing from any kind of surgery requires time; swelling, numbness and pain can accompany surgery for breast cancer. Afterward, a woman can expect to live an active, full life. Advances in reconstructive surgery and prostheses that resemble natural breast tissue help women who have had mastectomies retain their pre-surgexy appearance.

A Woman's Guide To Breast Health...

Treating Breast Cancer

Getting involved in a support group can really help in building your self-esteem

Other Kinds of Therapy

Breast cancer can respond to other treatrnents: radiation (or X-ray) therapy to suppress the cancer cells; chemotherapy (drugs that kill cancer cells); or hormonal therapy if the breast cancer appears sensitive to female hormones like estrogen or progesterone. Most of these treatments follow surgery to remove the major part of the cancer tissue.

Radiation (X-ray) Treatment

Radiation, like that found in X-rays, kills cancer cells. Doctors use radiation therapy after breast surgery to ensure that the cancer cells left behind after the operation are destroyed. The radiation treatments usually last from four to six weeks. Radiation, like many medical treatments, can have side effects. Be sure to discuss these side effects with your doctor before treatments begin.

Chemotherapy

Chemotherapy means treatment with drugs that kill cancer cells. Three or four doses of these drugs are given at a time, either by mouth (orally) or through the veins (intravenously). Some doctors give chemotherapy before surgery, but it is usually given after the surgical removal of breast tissue. This treatment can last up to nine months. Each drug used in chemotherapy has different side effects. Before beginning chemotherapy treatment, ask your doctor about the side effects of the drugs.

Hormone Therapy

Some cancer cells are sensitive to female hormones like estrogen and progesterone. These cancers may respond to hormone therapy. Estrogen and progesterone receptor assays will tell your doctor if you could benefit from hormone therapy.

Life Goes On

Breast cancer can be one of the most curable of cancers if it is found and treated early in the disease process. Most patients who have surgery and treatment for breast cancer can continue to lead healthy lives. But breast cancer can recur—usually within the first two years after the first treatment. Women who have had breast cancer must be alert for any changes in their bodies. Monthly breast self-exams, regular checkups with the doctor and yearly mammograms can detect new changes in the breasts or the return of cancer cells.

Supporting Recovery

As each year passes, the chances for a real cure grow. Many communities have support groups or self-help seminars for women who have or have had breast cancer as well as their families. A social worker, doctor, nurse, pastor or company nurse can refer you to one near you. Getting involved in a support group can really help in building your self-esteem and self-image at a very important time in your life.

Breast Cancer Dictionary

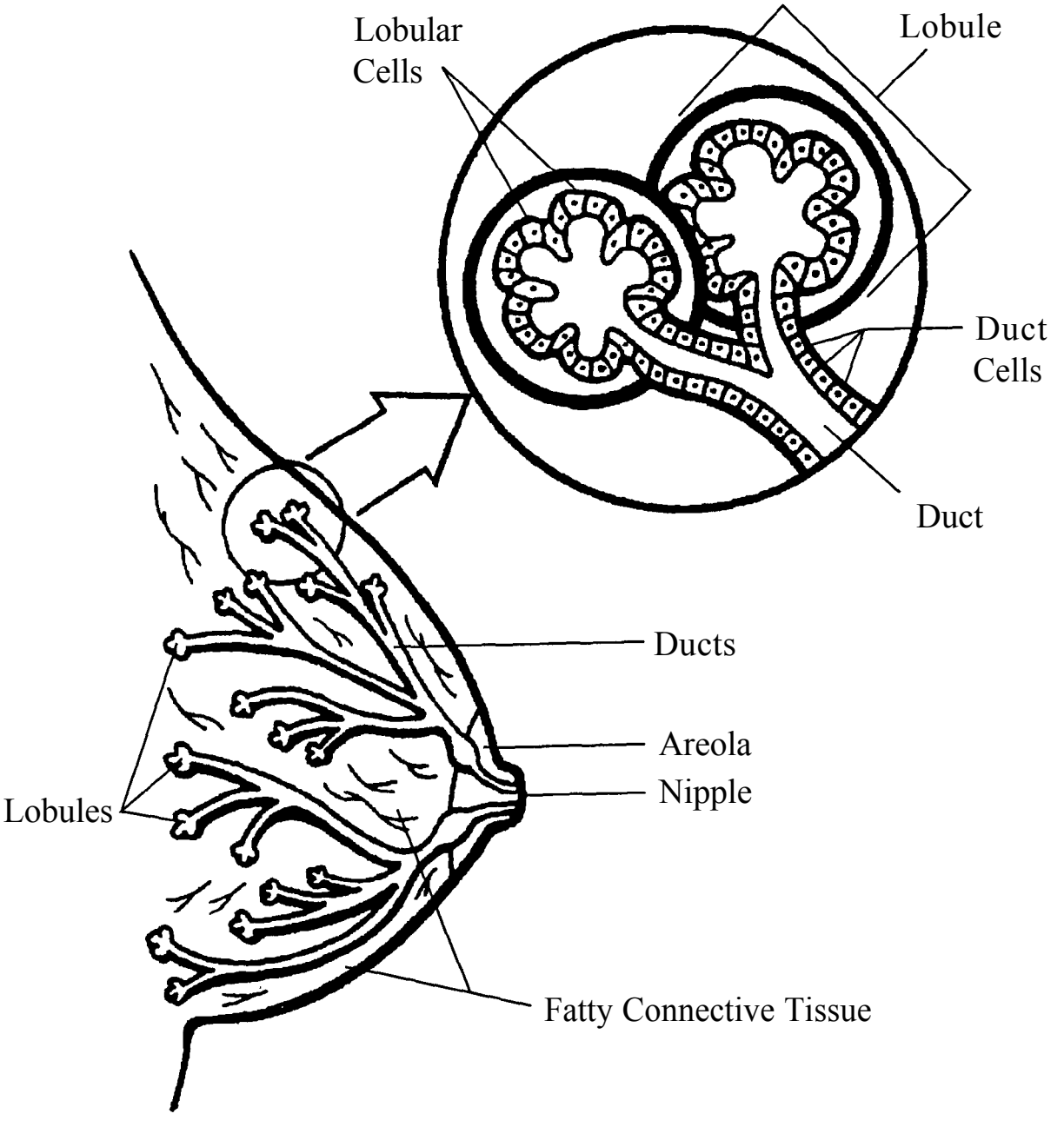
For more information about breast cancer contact the American Cancer Society:

1-800-ACS-2345

www.cancer.org

No. 4675-CC

Breast Structure



ablative therapy. Treatment that removes or destroys the function of an organ, as in surgical removal of the ovaries or the administration of some types of chemotherapy to ablate the ovaries, thus causing infertility.

acini. The sac-like part of the milk-producing glands in the breast. Several acini form a lobule.

adenocarcinoma. Cancer that starts in the glandular tissue, such as in the lobules or ducts of the breast.

adenoma. A benign growth starting in the glandular tissue. (*See also* fibroadenoma.)

adjuvant therapy. Treatment that is added to increase the effectiveness of a primary therapy. It usually refers to hormonal therapy, chemotherapy, or radiation added after surgery to increase the chances of curing the disease or keeping it in check.

adrenal gland. One adrenal gland is located near each kidney. Their main function is to produce hormones which regulate metabolism and control fluid balance and blood pressure. In addition, they produce small amounts of "male" hormones (androgens) and "female" hormones (estrogens and progesterone).

advanced cancer. A stage of cancer in which the disease has spread from the primary site to other parts of the body. When the cancer has spread only to the surrounding areas, it is called locally advanced. If it has spread further by traveling through the network of lymph glands (lymphatics) or in the bloodstream, it is called metastatic.

alopecia. Hair loss. This often occurs as a result of chemotherapy or radiation therapy to the head.

alternative treatment. *See* therapy.

androgen. A male sex hormone. Androgens may be used to treat recurrent breast cancer. Their effect is to block the activity of estrogen, thereby slowing growth of the cancer.

anesthesia. The loss of feeling or sensation as a result of drugs or gases. General anesthesia causes loss of consciousness ("puts you to sleep"). Local or regional anesthesia numbs only a specified area.

aneuploid. *See* ploidy.

antibiotic. The word means "destructive of life." Antibiotics are chemical substances, produced by living organisms or synthesized (created) in laboratories, for the purpose of killing other organisms that cause disease. Some cancer therapies interfere with the body's ability to fight off infection (they suppress the immune system), so antibiotics may be needed along with the cancer treatment to prevent or treat infections.

antibody. A protein in the blood that defends against invading foreign agents, such as bacteria. Invading agents contain certain chemical substances called antigens. Each antibody works against a specific antigen. (*See also* antigen.)

antiemetic. A drug that prevents or relieves nausea and vomiting, which are common side effects of chemotherapy. Antiemetic drugs can be used before, during, or after chemotherapy. Granisetron and ondansetron are examples of antiemetic drugs.

antiestrogen. A substance (for example, the drug tamoxifen) that blocks the effects of estrogen on tumors. Antiestrogens are used to treat breast cancers that depend on estrogen for growth.

antigen. A chemical substance that causes the body's immune system to react. This reaction often involves production of antibodies. For example, the immune system's response to antigens that are part of bacteria and viruses helps people resist infections. Cancer cells have certain antigens that can be detected by laboratory tests, and are important in cancer diagnosis and in monitoring response to treatment. Other cancer cell antigens play a role in immune reactions that may help the body's resistance against cancer.

antimetabolites. Antimetabolites are substances that interfere with the body's chemical processes, such as creating proteins, DNA, and other chemicals needed for cell growth and reproduction. In treating cancer, antimetabolite drugs disrupt DNA production, which in turn prevents cell division and growth of tumors. (*See also* DNA.)

areola. The dark area of flesh that surrounds the nipple of the breast.

aspirate. See needle aspiration.

asymptomatic. To be without noticeable symptoms of disease. Many cancers can develop and grow without producing symptoms, especially in the early stages. Screening

tests, such as mammography, try to discover developing cancers at the asymptomatic stage, when the chances for cure are usually highest. (*See also* screening.)

atypical. Not usual; abnormal. This often refers to the appearance of cancerous or precancerous cells. (*See also* hyperplasia.)

axilla. The armpit.

axillary dissection. A surgical procedure in which the lymph nodes in the armpit (axillary nodes) are removed and examined to find out if breast cancer has spread to those nodes.

benign. Not cancer; not malignant. The main types of benign breast problems are fibroadenomas and fibrocystic changes. (*See also* fibroadenoma, fibrocystic changes.)

bilateral. Affecting both sides of the body; for example, bilateral breast cancer is cancer occurring in both breasts at the same time (synchronous) or at different times (metachronous).

biologic response modifiers. Substances that boost the body's immune system to fight against cancer. (*See also* interferon.)

biopsy. A procedure in which tissue samples are removed from the body for examination of their appearance under a microscope to find out if cancer or other abnormal cells are present. A biopsy can be done with a needle or by surgery.

bone marrow transplant. A complex treatment that may be used when breast cancer is advanced or has recurred. The bone marrow transplant makes it possible to use very high doses of chemotherapy that would otherwise be impossible. *Autologous bone marrow transplant* means that the patient's own bone marrow is used. An *allogeneic bone marrow transplant* uses marrow from a donor whose tissue type closely matches the patient's. A portion of the patient's or donor's bone marrow is withdrawn, cleansed, treated, and stored. The patient is then given high doses of chemotherapy that kill the cancer cells but also destroy the remaining bone marrow, thus robbing the body of its natural ability to fight infection. The cleansed and stored marrow is given by transfusion (transplanted) to rescue the patient's immune defenses. Although this method has been widely reported by the media, and it has given good results in many people, it is not yet scientifically proven to be more effective than conventional therapies in treating breast cancer. It is a risky procedure that involves a lengthy and expensive hospital stay that

may not be covered by the patient's health insurance. The best place to have a bone marrow transplant is at a comprehensive cancer center or other facility that has the technical skill and experience to perform it safely.

bone scan. An imaging method that gives important information about the growth and health of bones, including the location of cancer that may have spread to the bones. It can be done as an outpatient procedure and is painless, except for the needle stick when a low-dose radioactive substance is injected into a vein. Images are taken to see where the radioactivity accumulates, indicating an abnormality.

bone (skeletal) survey. X-rays of the entire skeleton.

brain scan. An imaging method used to find abnormalities in the brain, including brain cancer and cancer that has spread to the brain from other places in the body. This procedure can be done in an outpatient clinic. It is painless, except for the needle stick when a radioactive substance is injected into a vein. The images taken will show where radioactivity accumulates, indicating an abnormality.

BRCA1. A gene which, when damaged (mutated), places a woman at greater risk of developing breast and/or ovarian cancer, compared with women who do not have the mutation. In a woman with a BRCA1 mutation, the estimated lifetime risk of developing breast cancer is 50% - 60% compared with 2% in the general population. A person who has this mutated gene has a 50% chance of passing on the gene to each of her children. A genetic test is available, but it is recommended only for women who are known to be at risk because several women in their family have had breast or ovarian cancer at an early age (before menopause). The ACS recommends that any women tested also receive genetic counseling.

BRCA2. A gene which, when damaged or mutated, puts the carrier at a much higher risk for developing breast cancer and/or ovarian cancer than the general population. In a woman with a BRCA2 mutation, the estimated lifetime risk of developing breast cancer is 50% - 60%. BRCA2 and BRCA1 together account for about 80% of the breast cancer that occurs in women with strong family histories of the disease. BRCA2 is thought also to raise the risk for breast cancer in men. A genetic test for BRCA2 is available but is only recommended for women or men with strong family histories of breast or ovarian cancer. The ACS recommends that any women tested also receive genetic counseling.

breast augmentation. Surgery to increase the size of the breast. (*See also* breast implant *and* mammoplasty.)

breast cancer. Cancer that starts in the breast. The main types of breast cancer are ductal carcinoma in situ, invasive ductal carcinoma, lobular carcinoma in situ, invasive lobular carcinoma, medullary carcinoma, and Paget's disease of the nipple (see definitions under these headings).

breast conservation therapy. Surgery to remove a breast cancer and a small amount of benign tissue around the cancer, without removing any other part of the breast. This procedure is also called lumpectomy, segmental excision, limited breast surgery, or tylectomy. The method may require an axillary dissection and/or radiation therapy in addition to the breast conservation surgery. (*See also* lumpectomy.)

breast implant. A manufactured sac that is filled with silicone gel (a synthetic material) or saline (sterile saltwater). The sac is surgically inserted to increase breast size or restore the contour of a breast after mastectomy. Because of concern about possible (but as yet unproven) side effects of silicone, silicone implants are presently available only to women who agree to participate in a clinical trial in which side effects are carefully monitored.

breast reconstruction. Surgery that rebuilds the breast contour after mastectomy. A breast implant or the woman's own tissue provides the contour. If desired, the nipple and areola may also be re-created. Reconstruction can be done at the time of mastectomy or any time later. (*See also* mammoplasty.)

breast self-exam (BSE). A technique of checking one's own breasts for lumps or suspicious changes. The method is recommended for all women over age 20, to be done once a month, usually at a time other than the days before, during, or immediately after her menstrual period.

breast specialist. A term describing health care professionals who have a dedicated interest in breast health. While they may acquire specialized knowledge in this area, medical licensing boards do not certify a specialty in breast care.

calcifications. Tiny calcium deposits within the breast, singly or in clusters, often found by mammography. These are also called microcalcifications. They are a sign of change within the breast that may be monitored by additional, periodic mammograms, or by immediate or delayed biopsy. They may be caused by breast cancer or by benign breast conditions.

cancer. A general term for more than 100 diseases in which malignant cells develop. Some exist quietly within the body for years without causing a problem. Others are aggressive, rapidly forming tumors that may invade and destroy surrounding tissue and in some cases travel through the lymph system or bloodstream to distant areas of the body.

cancer care team. The group of health care professionals who cooperate in the diagnosis, treatment, after-care, and counseling of people with cancer. The breast cancer care team may include any or all of the following and others: primary care physician and/or gynecologist, pathologist, oncology specialists (medical oncologist, radiation oncologist), surgeon, nurse, oncology nurse specialist, oncology social worker. Whether the team is linked formally or informally, there is usually one person who takes the job of "referee." (*See also* case manager.)

cancer cell. A cell that divides and reproduces abnormally and can spread throughout the body. (*See* metastasis.)

cancer-related checkup. A routine health examination for cancer in persons without obvious signs or symptoms of cancer. The goal of the cancer-related check-up is to find the disease, if it exists, at an early stage, when chances for cure are greatest. Clinical breast examinations, Pap smears, and skin examinations are examples of methods used in cancer-related check-ups. (*See also* detection.)

capsule formation. Scar tissue that may form around a breast (or other type of) implant as the body reacts to the foreign object. Sometimes called a contracture.

carcinogen. Any substance that causes cancer or helps cancer grow. For example, tobacco smoke contains many carcinogens that have been proven to dramatically increase the risk of lung cancer.

carcinoma. A malignant tumor that begins in the lining layer (epithelial cells) of organs. At least 80% of all cancers are carcinomas, and almost all breast cancers are carcinomas.

carcinoma in situ. An early stage of cancer, in which the tumor is still only in the structures of the organ where it first developed, and the disease has not invaded other parts of the organ or spread (metastasized). Most in situ carcinomas are highly curable.

case manager. The member of a cancer care team—usually a nurse or oncology nurse specialist—who coordinates the patient's care throughout diagnosis, treatment, and recovery. The case manager is a new concept that provides a guide through the complex system of health care by helping cut through red tape, getting responses to questions, managing crises, and connecting the patient and family to needed resources.

CT scan. *See* computed tomography.

cell. The basic unit of which all living things are made. Organs are clusters of cells that have developed specialized tasks. Cells replace themselves by splitting and forming new cells (mitosis). The processes that control formation of new cells and death of old cells are disrupted in cancer.

chemoprevention. Prevention or reversal of disease using drugs, chemicals, vitamins, or minerals. While this idea is not ready for widespread use, it is a very promising area of study. The Breast Cancer Prevention Trial is one such study, in which the drug tamoxifen is being tried to see if it will prevent breast cancer.

chemotherapy. Treatment with drugs to destroy cancer cells. Chemotherapy is often used in addition to surgery or radiation to treat cancer when metastasis is proven or suspected, when the cancer has come back (recurred), or when there is a strong likelihood that the cancer could recur. (*See also* adjuvant therapy.)

clinical trials. Research studies to test new drugs or other treatments to compare current, standard treatments with others that may be better.

computed tomography. An imaging procedure in which multiple x-rays are taken of a part of the body to produce cross-sectional images of internal organs. Except for injection of a dye (needed in some but not all cases), this is a painless procedure that can be performed in an out-patient clinic. It is often referred to as a "CT" or "CAT" scan.

contracture. A capsule or shell of dense scar-like tissue that may form around a breast implant. (*See also* capsule formation.)

cyst. A fluid-filled mass that is usually benign. The fluid can be removed for analysis. (*See* needle aspiration.)

cytology. The study or examination of cells: their structure, function and abnormalities to determine whether they are cancerous or benign.

cytotoxic. Toxic to cells; cell-killing.

detection. Finding disease. Early detection means that the disease is found at an early stage, before it has grown large or spread to other sites. (Note: Many forms of cancer can develop to an advanced stage without causing symptoms. Because of this, ovarian and pancreatic cancers, for example, are very difficult to detect.) Mammography is the principal way to detect breast cancer early. A mammogram can show a developing breast tumor before it can be felt by the woman herself or even by a highly skilled health care professional. Women participate in early detection by performing monthly breast self-examination and getting medical attention immediately for any suspicious lumps or discomfort in the breast, by having clinical breast exams by a health professional, and by having mammograms on the schedule recommended by the American Cancer Society.

diagnosis. Identifying a disease by its signs, symptoms, imaging procedures, and laboratory findings. The earlier a diagnosis of cancer is made, the better the chance for long-term survival.

diaphanography. Also called transillumination, this is a method of examining the breast. It is used primarily in younger women (40 years of age or less). The technique uses bright light to illuminate inner structures, in much the same way that children observe the blood and bones in their hands with a flashlight. It has limitations and by itself is not an adequate method of examination for suspicious lumps or thickenings in the breast.

dimpling. A pucker or indentation of the skin; on the breast, it may be a sign of cancer.

dissection. Surgery to divide, separate, or remove tissues. (*See also* axillary dissection.)

DNA. Abbreviation for deoxyribonucleic acid. DNA holds genetic information on cell growth, division, and function.

doubling time. The time it takes for a cell to divide and double itself. The doubling time of breast cancer cells depends on many things, such as the type of tumor, the resistance of the individual's body, and the location in which it tries to grow. A single cell needs 30 doublings to reach noticeable size (1 cm)—a billion cells. Cancers vary in doubling time from 8 to 600 days, averaging 100 to 120 days. Thus, a cancer may be present for many years before it can be felt. (*See also* cell.)

duct. A hollow passage for gland secretions. In the breast, a passage through which milk passes from the lobule (which makes the milk) to the nipple.

duct ectasia. Widening of the ducts of the breast, often related to breast inflammation called periductal mastitis. Duct ectasia is a benign (not cancerous) condition. Symptoms of this condition are a nipple discharge, swelling, retraction of the nipple, or a lump that can be felt.

ductal carcinoma in situ (DCIS). Cancer cells that start in the milk passages (ducts) and have not penetrated the duct walls into the surrounding tissue. This is a highly curable form of breast cancer that is treated with surgery or surgery plus radiation therapy. Also called intraductal carcinoma.

ductal papillomas. Small, finger-like, noncancerous growths in the breast ducts that may cause a bloody nipple discharge. These are most often found in women 45 to 50 years of age. When many papillomas exist, breast cancer risk is slightly increased.

edema. Build-up of fluid in the tissues, resulting in swelling. Edema of the arm can occur after radical mastectomy, axillary dissection of lymph nodes, or radiation therapy. (*See also* lymphedema.)

endocrine glands. Glands that release hormones into the bloodstream. The ovaries are one type of endocrine gland.

endocrine therapy. Manipulation of hormones for therapeutic purposes. (*See also* hormone therapy.)

epidemiology. The study of factors that have an impact on health and diseases by collecting and analyzing statistical data. In the field of cancer, epidemiologists are studying how many people have cancer; who gets specific types of cancer; and what factors (such as environment, job hazards, family patterns, and personal habits, such as smoking and diet) play a part in the development of cancer.

estrogen. A female sex hormone produced primarily by the ovaries, and in smaller amounts by the adrenal cortex. In women, levels of estrogen fluctuate on nature's carefully orchestrated schedule, regulating the development of secondary sex characteristics, including breasts; regulating the monthly cycle of menstruation; and preparing the body for fertilization and reproduction. In breast cancer, estrogen may

promote the growth of cancer cells. (See estrogen receptor assay, estrogen replacement therapy.)

estrogen receptor assay. Growth of normal breast cells and some breast cancers is stimulated by estrogen. Estrogen receptors are molecules that function as cells' "welcome mat" for estrogen circulating in the blood. Breast cancer cells without these receptors (called estrogen receptor negative or ER negative) are not affected by estrogen and are unlikely to respond to hormonal therapy. ER positive cancers are more likely to respond to hormonal therapy.

The estrogen receptor assay is a laboratory test done on a piece of the cancer in order to see whether estrogen receptors are present. (*See also* progesterone receptor assay.)

estrogen replacement therapy. The use of exogenous estrogen (estrogen not produced by the body; estrogen from other sources) after the body has ceased to produce it because of natural or induced menopause. This type of hormone therapy is often prescribed to alleviate symptoms of menopause and has been shown to provide protective effects against heart disease and osteoporosis in postmenopausal women. Since estrogen nourishes some types of breast cancer, scientists are working on the question of whether estrogen replacement therapy increases breast cancer risk. (*See also* estrogen, menopause, osteoporosis.)

etiology. The cause of a disease. In cancer, there are probably many etiologies, although research is showing that both genetics and lifestyle are major factors in many cancers.

extended radical mastectomy. *See* mastectomy.

fascia. A sheet or thin band of fibrous tissue that covers muscles and various organs of the body.

fat necrosis. The death of fat cells, usually following injury. Fat necrosis is a benign condition, but it can cause a breast lump, pulling of the skin, or skin changes that can be confused with breast cancer.

fibroadenoma. A type of benign breast tumor composed of fibrous tissue and glandular tissue. On clinical examination or breast self-examination, it usually feels like a firm, round, smooth lump. These usually occur in young women.

fibrocystic changes. A term that describes certain benign changes in the breast; also called fibrocystic disease. Symptoms of this condition are breast swelling or pain. Signs that a health care professional can observe on clinical breast examination are the presence of nodularity (nodules), lumpiness, and sometimes, nipple discharge. Because these signs sometimes mimic breast cancer, diagnostic mammography or microscopic examination of breast tissue may be needed to show that there is no cancer.

fibrosis. Formation of fibrous (scar-like) tissue. This can occur anywhere in the body.

fine needle aspiration. *See* needle aspiration.

flow cytometry. A test of tumor tissue to see how fast the tumor cells are reproducing and whether the tumor cells contain a normal or abnormal amount of DNA. This test is used to help predict how aggressive a cancer is likely to be. (See also ploidy, DNA, S-phase fraction.)

frozen section. Microscopic examination of a specimen of tissue that has been quick-frozen. This method gives a quick diagnosis, sometimes while the surgeon is waiting to complete a procedure. The diagnosis is confirmed in a few days by a more detailed study called a permanent section. (*See **also*** permanent section.)

galactocele. A clogged milk duct; a cyst filled with milk. It may occur in the breast during breastfeeding.

gene. A segment of DNA that contains information on hereditary characteristics such as hair color, eye color, and height as well as susceptability to certain diseases. Women who have BRCA1 or BRCA2 gene mutations (defects) have an inherited (genetic) tendency to develop breast cancer.

genetic. Related to genes. (*See **also*** gene.)

glands. Organs that produce and release substances used locally or elsewhere in the body.

grade. The grade of a breast cancer reflects how abnormal it looks under the microscope. There are several grading systems for breast cancer, but all divide cancers into those with the greatest abnormality (grade) or poorly differentiated, the least abnormality (grade 1 or moderately differentiated) and or intermediate features (grade 2 or moderately differentiated). Grading is done by the pathologist who examines the

biopsy specimen. It is important because higher grade cancers tend to grow and spread more quickly and have a worse prognosis.

graphic stress telethermometry (GST). A method of measuring surface heat from a distance. Some have used this method, plus computer analysis of heat patterns in the breast, to measure breast cancer risk. This is not a reliable method and is not in standard practice.

Halsted radical mastectomy. *See* mastectomy.

hematologist. A physician who specializes in diagnosis and treatment of conditions that arise in the blood and blood-forming tissues, including bone marrow.

hematoma. A collection of blood outside a blood vessel caused by a leak or injury; for example, the bruise that may appear after blood is drawn for lab work. Hematomas that occur in the breast after injury or after surgery may feel like a lump. As with other breast lumps, it's important to have this checked to be sure that it is indeed a hematoma and not a more serious problem.

hereditary cancer syndrome. Conditions associated with cancers that occur in multiple family members, because of an inherited, mutated gene.

high risk. Having a higher risk of developing cancer, compared with the general population. (*See also* risk factor.)

hormone. A chemical substance released into the body by the endocrine glands, such as the thyroid, adrenal, or ovaries. The substance travels through the bloodstream and sets in motion various body functions. For example, prolactin, which is produced in the pituitary gland, begins and sustains the production of milk in the breast after childbirth.

hormone receptor assay. A test to see whether a breast tumor is likely to be affected by hormones or if it can be treated with hormones. (*See also* estrogen receptor assay, progesterone receptor assay.)

hormone replacement therapy. *See* estrogen replacement therapy.

hormone therapy. Treatment with hormones, drugs that interfere with hormone production or hormone action, or surgical removal of hormone-producing glands to kill cancer cells or show their growth. The most common hormonal therapy for breast

cancer is the drug tamoxifen. Other hormonal therapies include megestrol, aminoglutethimide, androgens and surgical removal of the ovaries (oophorectomy). (*See also* tamoxifen.)

hyperplasia. An abnormal increase in the number of cells in a specific area, such as the lining of the breast ducts or the lobules. This overgrowth may be due to hormonal stimulation, or continuous irritation. By itself, hyperplasia is not cancerous, but when the proliferation is marked and/or the cells are atypical (unlike normal cells), the risk of cancer developing is greater.

hysterectomy. An operation to remove the uterus, through an incision in the abdomen or the vagina. Removal of the ovaries (oophorectomy) may be done at the same time. (*See also* oophorectomy.)

imaging. Any method used to produce a picture of internal body structures. Some imaging methods used to detect cancer are x-rays (a breast x-ray is called a mammogram), magnetic resonance imaging (MRI), bone scans, scintigraphy, computed tomography (CT) scans, and ultrasonography. (*See also* mammogram, bone scan, computed tomography, magnetic resonance imaging, ultrasonography.)

immune system. The complex system by which the body resists infection by microbes (such as bacteria or viruses) and rejects transplanted tissues or organs. The immune system may also help the body fight some cancers. (*See also* antibody, antigen, lymph nodes.)

immunocytochemistry or inimunohistochemistry. A laboratory test that uses antibodies to detect specific chemical antigens in cells or tissue samples viewed under a microscope. This procedure can be used to help detect and classify cancer cells. It is also one of the methods used for estrogen receptor assays and progesterone receptor assays. (*See also* monoclonal antibodies.)

immunology. Study of how the body resists infection and certain other diseases. Knowledge gained in this field is important to cancer treatments based on the principies of immunology. (*See also* immunotherapy.)

immunosuppression. A state in which the ability of the body's immune system to respond is decreased. This condition may be present at birth, may be caused by certain infections (such as human immunodeficiency virus or HIV), or by certain cancer

therapies, such as cytotoxic (cancer-cell killing) drugs, radiation, and bone marrow transplant action.

immunotherapy. Treatments that promote or support the body's immune system response to a disease, such as cancer.

infraclavicular nodes. Lymph nodes located beneath the clavicle (collar bone).

interferon. A protein produced by cells, interferon helps regulate the body's immune system, boosting activity when a threat, such as a virus, is detected. Scientists have learned that interferon helps fight against cancer, so it is used for immunotherapy of some types of cancer.

internal mammary nodes. Lymph nodes beneath the breast bone on each side. Some breast cancers may spread to these nodes.

intraductal papilloma. A benign tumor that starts in the duct system of the breast. It can cause discharge from the nipple.

intravenous (IV). A method of supplying fluids and medications, using a needle inserted in a vein.

invasive cancer. Cancer that has spread beyond the area it developed in, to involve adjacent tissues. For example, invasive breast cancers develop in milk glands (lobules) or milk passages (ducts) and spread to the adjacent fatty breast tissue. Some invasive cancers spread to distant areas of the body (metastasize), but others do not. Also called infiltrating cancer. (*See also* invasive ductal carcinoma, invasive lobular carcinoma.)

invasive ductal carcinoma. A cancer that starts in the milk passages (ducts) of the breast and then breaks through the duct wall, where it invades the fatty tissue of the breast. When it reaches this point, it has the potential to spread (metastasize) elsewhere in the breast, as well as to other parts of the body through the bloodstream and lymphatic system. Invasive ductal carcinoma is the most common type of breast cancer, accounting for about 80% of breast malignancies. Also known as infiltrating ductal carcinoma.

invasive lobular carcinoma. A cancer that arises in the milk-producing glands (lobules) of the breast and then breaks through the lobule walls to involve the adjacent fatty tissue. From this site, it may then spread elsewhere in the breast. About 15% of invasive breast cancers are invasive lobular carcinomas. It is often difficult to detect by

physical examination or even by mammography. Also called infiltrating lobular carcinoma.

lactation. Production of milk in the breast.

latissimus dorsi flap procedure. A method of breast reconstruction that uses the long flat muscle of the back, by rotating it to the chest area.

leukemia. Cancer of the cells that form the blood. People with leukemia often have a noticeable increase in leukocytes (white blood cells). Leukemia can develop as a consequence of some types of breast cancer therapy.

limited breast surgery. Also called lumpectomy, segmental excision, and tylectomy. It removes the breast cancer and a small amount of tissue around the cancer, but preserves most of the breast. It is almost always combined with axillary lymph node removal and is followed by radiation therapy. (*See also* lumpectomy.)

linear accelerator. A machine used in radiation therapy to treat cancer. It generates gamma rays and electron beams.

lobular carcinoma in situ (LCIS). A very early type of breast cancer that develops within the milk-producing glands (lobules) of the breast and does not penetrate through the wall of the lobules. Researchers think that most cases of lobular carcinoma in situ do not progress to invasive lobular cancer. However, having this type of cancer places a woman at increased risk of developing an invasive breast cancer later in life. For this reason, it's important for women with lobular carcinoma in situ to have a physical examination three times a year and an annual mammogram.

localized breast cancer. A cancer that started in the breast and is confined to the breast.

lump. Any kind of mass that can be felt in the breast or elsewhere in the body.

lumpectomy. Surgery to remove the breast tumor and a small amount of surrounding normal tissue. (*See also* breast conservation therapy, two-step procedure.)

lymph. Clear fluid that passes within the lymphatic system and contains cells known as lymphocytes. These cells are important in fighting infections and may also have a role in fighting cancer.

lymph nodes. Small bean-shaped collections of immune system tissue such as lymphocytes, located along lymphatic vessels. They remove waste and fluids from lymph and help fight infections. Also called lymph glands. (*See also* lymph, lymphatic system).

lymphatic system. The tissues and organs (including bone marrow, spleen, thymus, and lymph nodes) that produce and store lymphocytes (cells that fight infection) and the channels that carry the lymph fluid. The entire lymphatic system is an important part of the body's immune system. Invasive cancers sometimes penetrate the lymphatic vessels and metastasize (spread) to lymph nodes.

lymphedema. Swelling in the arm caused by excess fluid that collects after lymph nodes and vessels are removed by surgery or treated by radiation. This condition is usually painful and can be persistent.

lymphoma. A cancer of lymphocytes (a type of white blood cell) that usually develops in lymph nodes. About 5% of cancers are lymphomas. The two main types of lymphomas are Hodgkin's disease and non-Hodgkin's lymphomas. Lymphoma can occur as a result of some types of cancer therapies.

magnetic resonance imaging (MRI). A method of obtaining cross-sectional images of the inside of the body. Instead of using x-rays, MRI uses a powerful magnet and transmits radio waves through the body; the images appear on a computer screen as well as on film. Like x-rays, the procedure is physically painless, but some people find it psychologically uncomfortable to be in the small core of the MRI machine. Also called nuclear magnetic resonance (NMR).

malignant tumor. A mass of cancer cells that may invade surrounding tissues or spread (metastasize) to distant areas of the body. *See* cancer.

mammogram, mammography. An x-ray of the breast; the principal method of detecting breast cancer in women over 40. Mammograms are made using a special type of x-ray machine that is used only for this purpose. It has two plates. The lower plate is metal and has a drawer for the film cassette. The bare breast is placed on this plate. The upper plate, which is clear plastic, is lowered and compresses the breast. Compression is necessary to obtain a clear image of the interior structures of the breast. The compression is maintained for only a few seconds—long enough for the technician to go to the control panel and take the picture. The procedure is then repeated with the other breast. A mammogram can show a developing breast tumor before it is large enough to be felt

by a woman or even by a highly skilled health care professional. *Screening mammography* is used for early detection of breast cancer in women without any breast symptoms. *Diagnostic mammography* is used to help characterize breast masses or determine the cause of other breast symptoms.

mammoplasty. Plastic surgery to reconstruct the breast or to change the shape, size, or position of the breast. Reduction mammoplasty reduces the size of the breast. Augmentation mammoplasty enlarges the breast, usually with implants.

mastectomy. Surgery to remove all or part of the breast and sometimes other tissue. *Extended radical mastectomy* removes the breast, skin, nipple, areola, chest muscles (pectoral major and minor), and all axillary and internal mammary lymph nodes on the same side. *Halsted radical mastectomy* removes the breast, skin, nipple, areola, both pectoral muscles, and all axillary lymph nodes on the same side. *Modified radical mastectomy* removes the breast, skin, nipple, areola, and most of the axillary lymph nodes on the same side, leaving the chest muscles intact. *Partial mastectomy* removes less than the whole breast taking only part of the breast in which the cancer occurs and a margin of healthy breast tissue surrounding the tumor. *Subcutaneous mastectomy* is surgery to remove internal breast tissue. The nipple and skin are left intact. *Prophylactic mastectomy* is a subcutaneous mastectomy done before any evidence of cancer can be found, for the purpose of preventing cancer. This procedure is sometimes recommended for women at very high risk of breast cancer. *Quadrantectomy* is a partial mastectomy in which the quarter of the breast that contains a tumor is removed. *Segmental mastectomy* is a partial mastectomy. *Simple mastectomy* or *total mastectomy* removes only the breast and areola.

mastitis. Inflammation or infection of the breast.

mastopexy. Surgery to lift a breast that sags.

medical oncologist. *See* oncologist.

medullary carcinoma. A special type of infiltrating ductal carcinoma with especially Sharp boundaries between tumor tissue and normal tissue. About 5% of breast cancers are medullary carcinomas. The outlook (prognosis) for this kind of cancer is considered to be better than average.

menarche. A woman's first menstrual period. Early menarche (before age 12) is a risk factor for breast cancer, possibly because the earlier a woman's periods begin, the longer her exposure to estrogen.

menopause. The time in a woman's life when monthly cycles of menstruation cease forever and the level of hormones produced by the ovaries decreases. Menopause usually occurs in the late 40s or early 50s, but it can also be caused by surgical removal of both ovaries (oophorectomy), or by some chemotherapies that destroy ovarian function. (*See also* estrogen replacement therapy.)

metachronous. At different times. (*See also* bilateral.)

metastasis. The spread of cancer cells to distant areas of the body by way of the lymph system or bloodstream.

microcalcifications. *See* calcifications.

micrometastases. The spread of cancer cells in groups so small that they can only be seen under a microscope.

modified radical mastectomy. *See* mastectomy.

monoclonal antibodies. Antibodies manufactured in the laboratory and designed to seek out as targets specific chemicals (antigens). Monoclonal antibodies which have been attached to chemotherapy drugs or radioactive substances are being studied for their potential to seek out antigens unique to cancer cells and deliver these treatments directly to the cancer, thus killing the cancer cell and not harming healthy tissue. Monoclonal antibodies are often used in immunocytochemistry to help detect and classify cancer cells. Other studies are being done to see if radioactive atoms attached to monoclonal antibodies can be used in imaging tests to detect and locate small groups of cancer cells. (*See also* antibody, antigen, immunocytochemistry.)

multicentric breast cancer. Breast cancer occurring in multiple areas of a breast.

needle aspiration. A type of needle biopsy. Removal of fluid from a cyst or cells from a tumor. In this procedure, a needle and syringe (like those used to give injections) is used to pierce the skin, reach the cyst or tumor, and with suction, draw up (aspirate) specimens for biopsy analysis. If the needle is thin, the procedure is called a fine needle aspiration or FNA. (*See also* needle biopsy.)

needle biopsy. Removal of fluid, cells, or tissue with a needle for examination under a microscope. There are two types: fine needle aspiration (also called FNA or needle aspiration) and core biopsy. FNA uses a thin needle and syringe (like those used to give injections) to pierce the skin and draw up (aspirate) fluid or small tissue fragments from a cyst or tumor. A core needle biopsy uses a thicker needle to remove a cylindrical sample of tissue from a tumor.

needle localization. A procedure used to guide a surgical breast biopsy when the lump is difficult to locate or in areas that look suspicious on the x-ray but do not have a distinct lump. After an injection of local anesthesia to numb the area, a thin needle is placed into the breast. X-rays are taken and used to guide the needle to the suspicious area. The surgeon then uses the path of the needle as a guide to locate the abnormal area to be removed. (*See also* wire localization.)

neoplasm. An abnormal growth (tumor) that starts from a single altered cell, a neoplasm may be benign or malignant. Cancer is a malignant neoplasm.

nipple. The tip of the breast; the pigmented projection in the middle of the areola. The nipple contains the opening of milk ducts from the breast.

nipple discharge. Any fluid coming from the nipple. It may be clear, milky, bloody, tan, gray, or green.

nodal status. Indicates whether a breast cancer has spread (node-positive) or has not spread (node-negative) to lymph nodes in the armpit (axillary nodes). The number and site of positive axillary nodes can help predict the risk of cancer recurrence.

node. *See* lymph node.

nodule. A small, solid lump that can be located by touch.

Nolvadex. Trade name for tamoxifen, an antiestrogen drug commonly used in breast cancer therapy. (*See also* antiestrogen, tamoxifen, hormonal therapy.)

normal hormonal changes. Changes in breast and other tissues that are caused by fluctuations in levels of female hormones during the menstrual cycle.

nuclear magnetic resonance (NMR). *See* magnetic resonance imaging.

nuclear medicine scan. A method for localizing diseases of internal organs such as the brain, liver, or bone, in which small amounts of a radioactive substance (isotope) are injected into the bloodstream. The isotope is concentrated in certain organs. A scintillation camera is used to produce an image of the organ and detect areas of disease. Except for the injection, this method of imaging is painless.

nucleus. The center of a cell where the DNA is housed and replicated. Studying the size and shape of a cell's nucleus under the microscope can help pathologists distinguish breast cancer cells from benign breast cells.

nulliparous. A woman who has never given birth to a child.

nurse practitioner. A registered nurse (RN) who has completed additional courses and specialized training. Nurse practitioners can work with or without the supervision of a physician. They take on additional duties in diagnosis and treatment of patients, and in many states they may write prescriptions. (*See also* oncology nurse specialist.)

oncogene. A type of gene found in cancer cells. When these genes are abnormally "turned on" (activated), they cause excessive growth and other characteristics of malignancy.

oncologist. A doctor who is specially trained in the diagnosis and treatment of cancer. *Medical oncologists* specialize in the use of chemotherapy and other drugs to treat cancer. *Radiation oncologists* specialize in the use of x-rays (radiation) to-kill tumors.

oncology nurse specialist. A registered nurse who has taken additional courses and specialized training in the care of cancer patients. Oncology nurse specialists may prepare and administer treatments, monitor patients, prescribe and provide aftercare, and teach and counsel patients and their families. Some oncology nurse specialists are also certified nurse practitioners. (*See also* case manager, nurse practitioner.)

oncology social worker. A person with a master's degree in social work who has specialized in working with cancer patients. The oncology social worker provides counseling and assistance to people with cancer and their families, especially in dealing with the non-medical crises that can result from cancer, such as financial problems, housing when treatments must be taken at a facility far away from home, and child care.

one-step procedure. Surgery during which the procedure to diagnose the presence of breast cancer *(see* biopsy) is followed immediately by treatment (such as mastectomy). The patient is given general anesthesia and does not know until she wakes up if the diagnosis was cancer or if a mastectomy was performed. Once the only option in breast cancer, the one-step procedure is now rarely used. (*See also* two-step procedure.)

oophorectomy. Surgery to remove the ovaries.

osteoporosis. Breakdown of bone, resulting in diminished bone mass and reduced bone strength. Osteoporosis can cause pain, deformity (especially of the spine), fractures (broken bones). This condition is common among postmenopausal women. (*See also* estrogen replacement therapy.)

ovary. Reproductive organ in the female pelvis. Normally a woman has two ovaries. They contain the eggs (*ova*) that, when joined with sperm, result in pregnancy. Ovaries are also the primary source of estrogen. (*See also* estrogen.)

Paget's disease of the nipple. A rare form of breast cancer that begins in the milk passages (ducts) and spreads to the skin of the nipple and areola. This affected skin may appear crusted, scaly, red, or oozing. The prognosis is generally better if these nipple changes are the only sign of breast disease and no lump can be felt.

palliative treatment. Therapy that relieves symptoms, such as pain, but is not expected to cure the disease. Its main purpose is to improve the patient's quality of life.

palpation. Using the hands to examine. A palpable mass in the breast is one that can be felt.

partial mastectomy. *See* mastectomy.

pathologist. A physician who specializes in diagnosis and classification of diseases by laboratory tests (such as examination of tissue and cells under a microscope). The pathologist determines whether a lump is benign or cancerous.

pectoral muscles. Muscles attached to the front of the chest wall and upper arms. The larger group is called *pectoralis major,* and a smaller group is called *pectoralis minor.* Because these muscles are next to the breast, breast cancer may sometimes spread to the pectoral muscles.

permanent section. Preparation of tissue for microscopic examination. The tissue is soaked in formaldehyde, processed in various chemicals, surrounded by a block of wax, sliced very thin, attached to a microscope slide and stained. This usually takes 1-2 days. It provides a clear view of the specimen so that the presence or absence of cancer can be determined. (*See also* frozen section.)

placebo. An inert, inactive substance that may be used in clinical trials to compare the effects of a given treatment with no treatment.

ploidy. A measure of the amount of DNA contained in a cell. Ploidy is a characteristic (marker) that helps predict how aggressive a cancer is likely to be. Cancers with the same amount of DNA as normal cells are called diploid and those with either more or less than that amount are aneuploid. About two-thirds of breast cancers are aneuploid.

precancerous. *See* premalignant.

predisposition. Susceptibility to a disease that can be triggered under certain conditions. For example, some women have a family history of breast cancer and are therefore predisposed (but not necessarily destined) to develop breast cancer.

premalignant. Abnormal changes in cells that may, but do not always, become cancer. Also called precancerous.

prevalence. A measure of the proportion of persons in the population with a particular disease at a specified time.

primary cancer. The site where cancer begins. Primary cancer is usually named after the organ in which it starts (for example, cancer that starts in the breast is always breast cancer even if it metastasizes to other organs, such as bones or lungs).

progesterone. A female sex hormone released by the ovaries to prepare the uterus for pregnancy and the breasts for milk production (lactation).

progesterone receptor assay. A laboratory test done on a piece of the breast cancer that shows whether the cancer depends on progesterone for growth. Progesterone receptors are tested along with estrogen receptors for more complete information on the hormone sensitivity of a cancer, and how best to treat it. (*See also* estrogen receptor assay).

prognosis. A prediction of the course of disease; the outlook for the cure of the patient. For example, women with breast cancer that was detected early and received prompt treatment have a good prognosis.

prolactin. A hormone released from the pituitary gland that prompts milk production (lactation).

prophylactic mastectomy. *See* mastectomy.

prosthesis. An artificial form, such as a breast prosthesis, that can be worn under the clothing after a mastectomy. (Plural: prostheses.)

protocol. A formalized outline or plan such as a description of what treatments a patient will receive and exactly when each should be given.

quadrantectomy. *See* mastectomy.

radiation oncologist. *See* oncologist.

radical (Halsted or standard) mastectomy. *See* mastectomy.

radioisotope. A type of atom that is unstable and prone to break up (decay). Decay releases small fragments of atoms and energy. Exposure to certain radioisotopes can cause cancer. Use of radioisotopes under controlled conditions can be used to treat cancer (*see* radiotherapy). In certain imaging procedures, radioisotopes are injected. They travel through the body and collect in areas where the disease is active, showing up as highlighted areas on the images (*see* nuclear medicine scan). In breast cancer, radioisotopes are used to check for metastasis to the bones.

radiologic technologist. A health professional (not a physician) trained to properly position patients for x-rays, to load film and take the images, and to develop and check the images for quality. Since mammograms (breast x-rays) are done on a machine that is used only for mammograms, the technologist must have special training in mammography. The films taken by the technologist are sent to a radiologist to be read.

radiologist. A physician who has taken additional training in interpretation of x-rays and other types of diagnostic imaging studies (for example, ultrasound and magnetic resonance imaging; *see* imaging).

radiotherapy. Treatment with radiation to destroy cancer cells. Sources of radiation used include linear accelerators, cobalt, and betatrons. This type of treatment may be used to reduce the size of a cancer before surgery, or to destroy any remaining cancer cells after surgery. Also called irradiation and radiation therapy.

Reach to Recovery. A visitation program of the American Cancer Society for women who have a personal concern about breast cancer. Carefully selected and trained volunteers who have successfully adjusted to breast cancer and its treatment provide information and support to women newly diagnosed with the disease.

reconstructive mammoplasty. *See* mammoplasty, latissimus dorsi flap procedure, transverse rectus abdominus muscle flap procedure.

rectus abdominus flap procedure. See transverse rectus abdominus muscle flap procedure.

recurrence. Cancer that has come back after treatment. *Local recurrence* is at the same site as the original cancer. *Regional recurrence* is in the lymph nodes near the site of origin. *Distant recurrence* is in organs or tissues further from the original site than the regional lymph nodes (such as the lungs, liver, bone marrow, or brain). *Metastasis* means that the disease has recurred at a distant site.

reduction mammoplasty. *See* mammoplasty.

regimen. A strict, regulated plan (such as diet, exercise, or other activity) designed to reach certain goals. In cancer treatment, a plan to treat cancer.

regional involvement. The spread of breast cancer from its original site to nearby areas such as the chest muscles or axillary lymph nodes, but not to distant sites such as other organs.

rehabilitation. Activities to adjust, heal, and return to a full, productive life after injury or illness. This may involve physical restoration (such as the use of prostheses, exercises, and physical therapy), counseling, and emotional support.

relapse. Reappearance of cancer after a disease-free period. *See* recurrence.

remission. Complete or partial disappearance of the signs and symptoms of cancer in response to treatment; the period during which a disease is under control. A remission may not be a cure.

risk factor. Anything that increases a person's chance of getting a disease, such as cancer. Known risk factors for breast cancer include: family history of the disease especially in one's mother or sister; beginning menstrual periods at a young age (early menarche) and ending periods at an older age (later menopause); and obesity.

saline breast implant. *See* breast implant.

saline. Saltwater solution.

sarcoma. A malignant tumor growing from connective tissues, such as cartilage, fat, muscle, or bone. Several types of sarcoma (such as angiosarcoma, liposarcoma, and malignant phylloides tumor) can develop in the breast, and they differ in their prognosis.

scan. A study using either x-rays or radioactive isotopes to produce images of internal body organs. (*See also* bone scan, brain scan, computed tomography (CT) scan, magnetic resonance imaging (MRI), nuclear medicine scan.)

scintillation camera. Device used in nuclear medicine scans to detect radioactivity and produce images that help diagnose cancer and other diseases.

screening. The search for disease, such as cancer, in people without symptoms. Screening may refer to coordinated programs in large populations. The principal screening measure for breast cancer is mammography.

screening mammography. *See* mammography and screening.

secondary tumor. A tumor that forms as a result of spread (metastasis) of cancer from its site of origin.

segmental mastectomy. *See* mastectomy.

segmental resection. *See* mastectomy.

side effects. Unwanted effects of treatment, such as hair loss caused by chemotherapy and fatigue caused by radiation therapy.

silicone gel. Synthetic material used in breast implants because of its flexibility, strength, and texture, which is similar to the texture of the natural breast. Silicone gel breast implants are available for women who have had breast cancer surgery, but only if they participate in a clinical trial. (*See also* breast implant.)

simple mastectomy *See* mastectomy.

skin dimpling. *See* dimpling.

S-phase fraction (SPF). The percentage of cells that are replicating their DNA. DNA replication usually indicates that a cell is getting ready to split into two new cells. A low SPF is a sign that .a tumor is slow-growing; a high SPF shows that the cells are dividing rapidly and the tumor is growing quickly.

staging. The process of determining and describing the extent of cancer. Staging of breast cancer is based on the size of the tumor, whether regional axillary lymph nodes are involved, and whether distant spread (metastasis) has occurred. Knowing the stage at diagnosis is essential in selecting the best treatment and predicting a patient's outlook for survival.

standard therapy, standard treatment. *See* therapy.

stereotactic needle biopsy. A method of needle biopsy that is useful in some cases in which calcifications or a mass can be seen on mammogram but cannot be located by touch. Computerized equipment maps the location of the mass and this is used as a guide for the placement of the needle. (*See also* needle aspiration, needle biopsy.)

stomatitis. Inflammation or ulcers of the lips, gums, tongue, palate, floor of the mouth, or other tissues in the mouth. This condition can result as a side effect of some chemotherapies.

subcutaneous mastectomy. *See* mastectomy.

supraclavicular nodes. Lymph nodes that are above the collarbone (clavicle).

survival rate. The percentage of people who live a certain period of time. For example, the 5-year survival rate for women with localized breast cancer (including all women living five years after diagnosis, whether the patient was in remission, disease-free, or under treatment) was 78% in the 1940s, but in the 1990s, it is over 97%.

synchronous. At the same time. (*See also* bilateral.)

systemic disease. In breast cancer, this term means that the tumor that originated in the breast has spread to distant sites, such as the liver, brain, bones, or lungs.

systemic therapy. Treatment that reaches and affects cells throughout the body; for example, chemotherapy.

tamoxifen (brand name: Nolvadex). A drug that blocks estrogen; an antiestrogen drug. Blocking estrogen is desirable in some cases of breast cancer because estrogen promotes their growth.

therapy. Any of the measures taken to treat a disease. *Unproven therapy* is any therapy that has not been scientifically tested and approved. Use of an unproven therapy instead of standard therapy is called *alternative therapy.* Some alternative therapies have dangerous or even life-threatening side effects. For others, the main danger is that a patient may lose the opportunity to benefit from standard therapy. *Complementary therapy,* on the other hand, refers to therapies used in addition to standard therapy. Some complementary therapies may help relieve certain symptoms of cancer, relieve side effects of standard cancer therapy, or improve a patient's sense of well-being. The ACS recommends that patients considering use of any alternative or complementary therapy discuss this With their health care team. Information regarding specific therapies is available from the Society's toll-free information number 1-800-ACS-2345.

thermography. A method in which heat from the breast is measured and mapped. Also called a thermogram, this method is not reliable in detecting breast cancer.

tissue. A collection of cells, united to perform a particular function.

total mastectomy. *See* mastectomy.

TRAM flap. *See* transverse rectus abdominus muscle flap procedure.

transillumination. *See* diaphanography.

transverse rectus abdominus muscle flap procedure. A method of breast reconstruction in which tissue from the lower abdominal wall which receives its blood supply from the rectus abdominus muscle is used. The tissue from this area is moved up to the chest to create a breast mound and usually does not require an implant. Moving muscle and tissue from the lower abdomen to the chest results in flattening of the lower abdomen (a "tummy tuck"). Also called a TRAM flap or rectus abdominus flap procedure.

tumor. A lump or mass which has formed due to excessive accumulation of abnormal cells. "Tumor" is not a precise medical term. Tumors can be benign (not cancerous) or malignant (cancerous).

two-step procedure. A method in which the breast biopsy for diagnosis and breast surgery for treatment (such as lumpectomy or mastectomy, if the diagnosis is breast cancer) are performed as two separate procedures, after an interval of days or weeks. This method is strongly preferred by women and their health care teams because it allows time to consider all options. (*See also* one-step procedure.)

tylectomy. *See* lumpectomy.

ultrasonography (ultrasound). An imaging method in which high-frequency sound waves are used to outline a part of the body. High-frequency sound waves are transmitted through the area of the body being studied. The sound wave echoes are picked up and displayed on a television screen. This painless method is sometimes useful in distinguishing fluid-filled cysts from solid tumors. It is sometimes used to guide needle biopsy of breast abnormalities too small to feel. No radiation exposure occurs.

unilateral. Affecting one side of the body. For example, unilateral breast cancer occurs in one breast only. (*See also* bilateral).

unproven methods of cancer management. *See* therapy, unproven.

vaccine. Inactivated, killed, or weakened disease-causing organisms (for example, mumps or measles virus) that are injected into the body for the purpose of developing resistance to the disease. The body's immune system responds to the vaccine by forming antibodies and activating certain immune system cells that are specifically targeted to those particular organisms. The result is that the body is then resistant (immune) to the

disease for a specific period of time; in some cases, the immunity lasts forever. Development of a cancer vaccine is a subject of intense research. (*See* immune system *and* antibody.)

vaginitis. Any inflammation of the vagina. *Atrophic vaginitis* is an inflammation of the vagina in which vaginal tissue becomes thin and dry. This condition occurs after menopause and is caused by lack of estrogen. (*See also* menopause.) An estrogen cream may be prescribed to relieve this problem. Vaginitis is a common side effect of chemotherapy.

white blood cells. Several types of blood cells that help defend the body against infections. Certain cancer treatments (particularly chemotherapy) can reduce the number of these cells and make a patient more vulnerable to infections. Some types of white blood cells may also help the body fight certain cancers.

wire localization. A procedure used to guide a surgical breast biopsy when the lump is difficult to locate or in areas that look suspicious on the x-ray but do not have a distinct lump. After numbing the area with local anesthetic, a hollow needle is placed into the breast and x-rays are taken to guide the needle to the suspicious area. A thin wire is inserted through the center of the needle. A small hook at the end of the wire keeps it in place. The hollow needle is then removed, and the surgeon uses the path of the wire as a guide to locate the abnormal area to be removed. (*See also* needle localization).

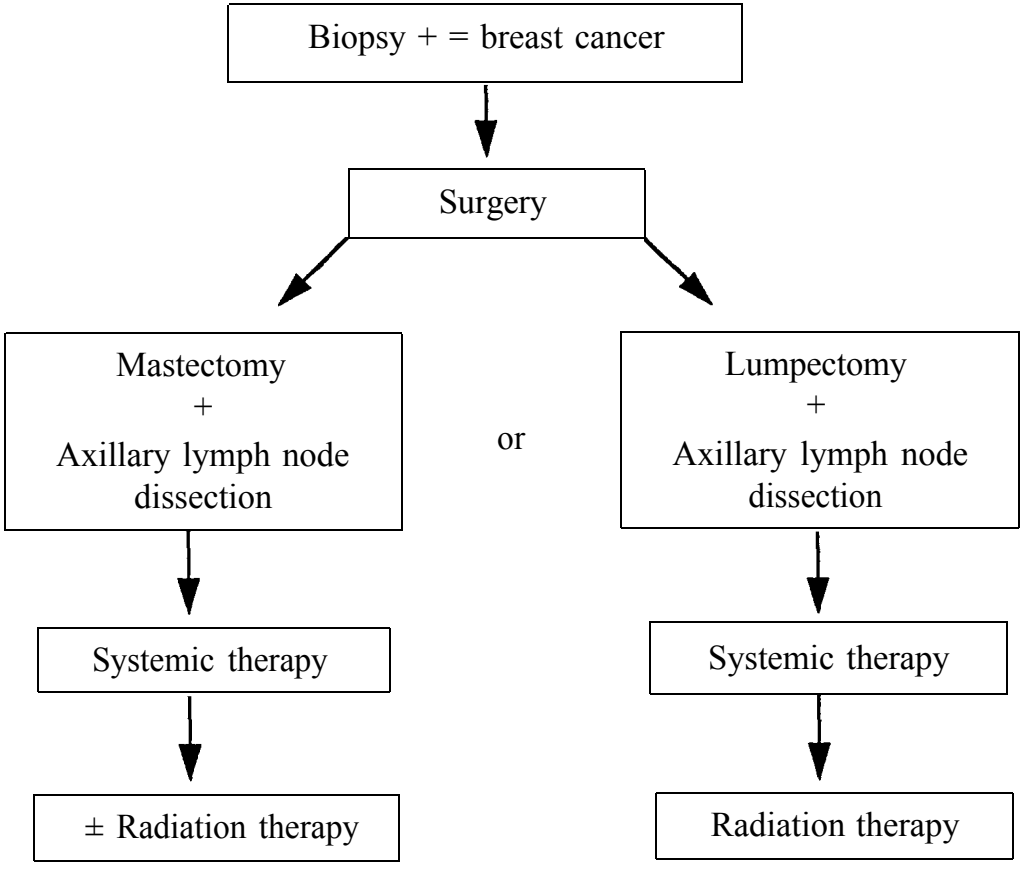
xeroradiography (xeromammography). An outdated form of mammography that records the image of the breast on paper rather than on film. This method is rarely used now.

x-rays. One form of radiation that can, at low levels, produce an image of the body on film, and at high levels, can destroy cancer cells.

5-Year Survival Rate for Breast Cancer by Stage

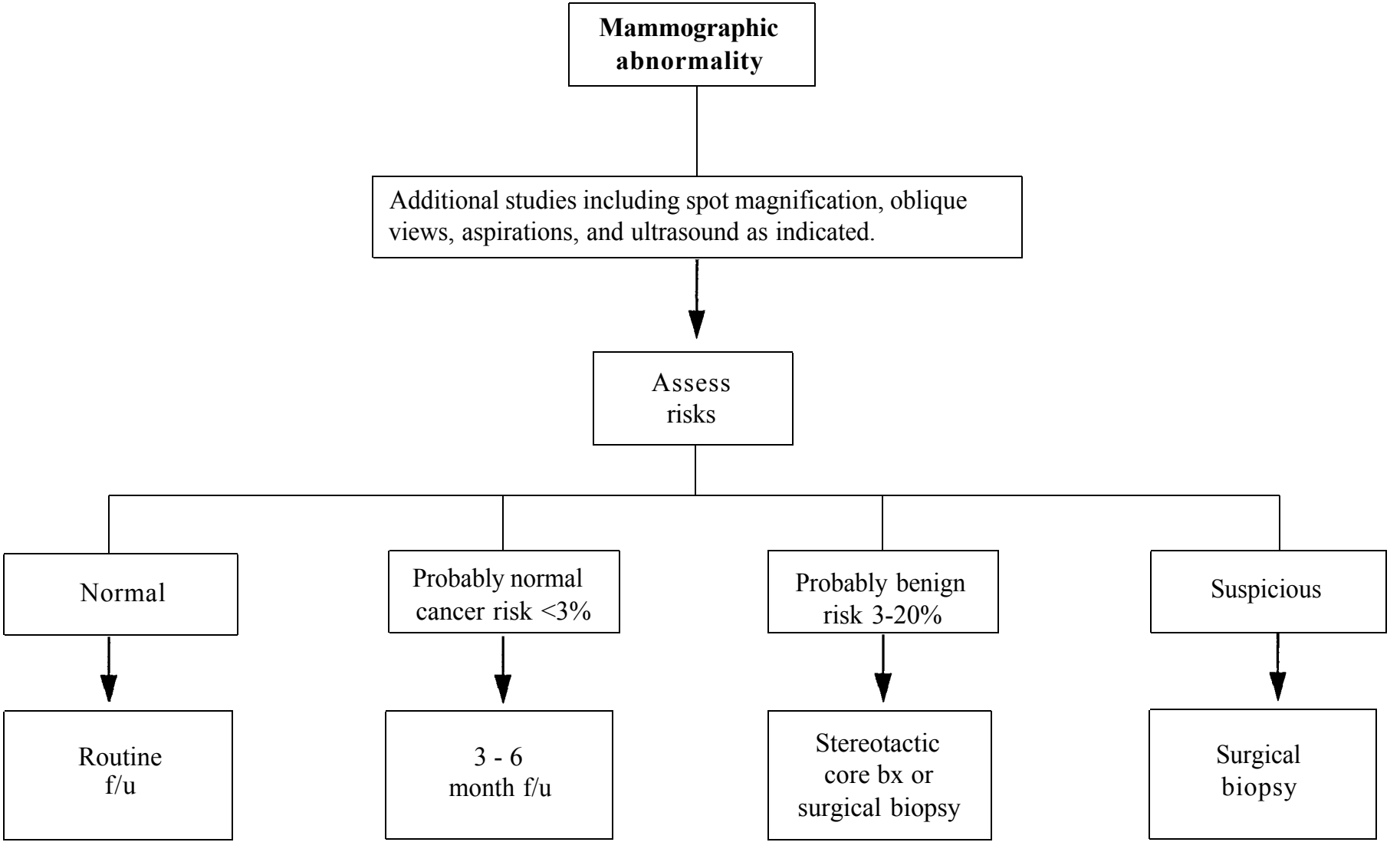
Stage	5-year survival (%)
0	99
I	92
IIA	82
IIB	65
IIIA	47
IIIB	44
IV	14

What happens after a breast cancer is found?

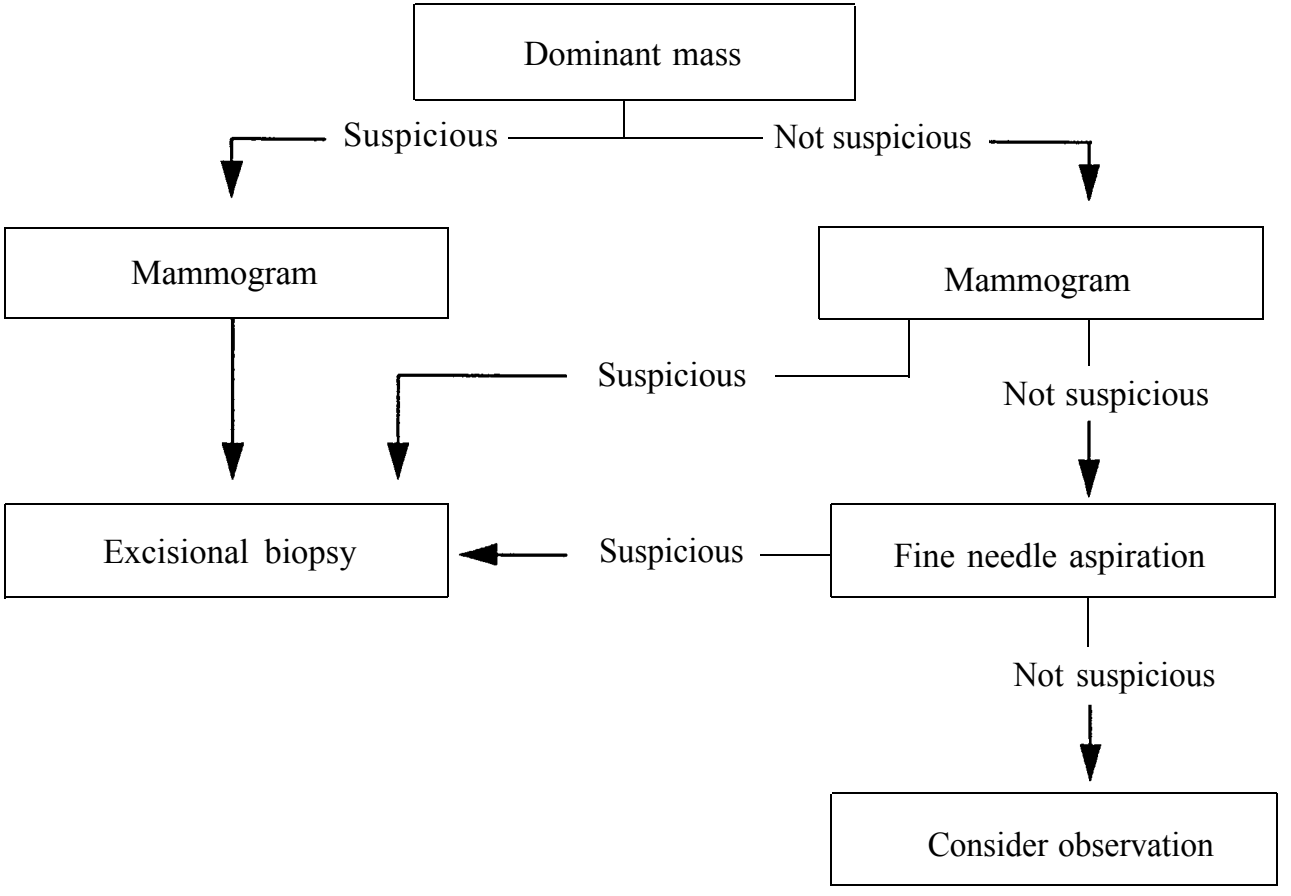


Biopsy techniques-

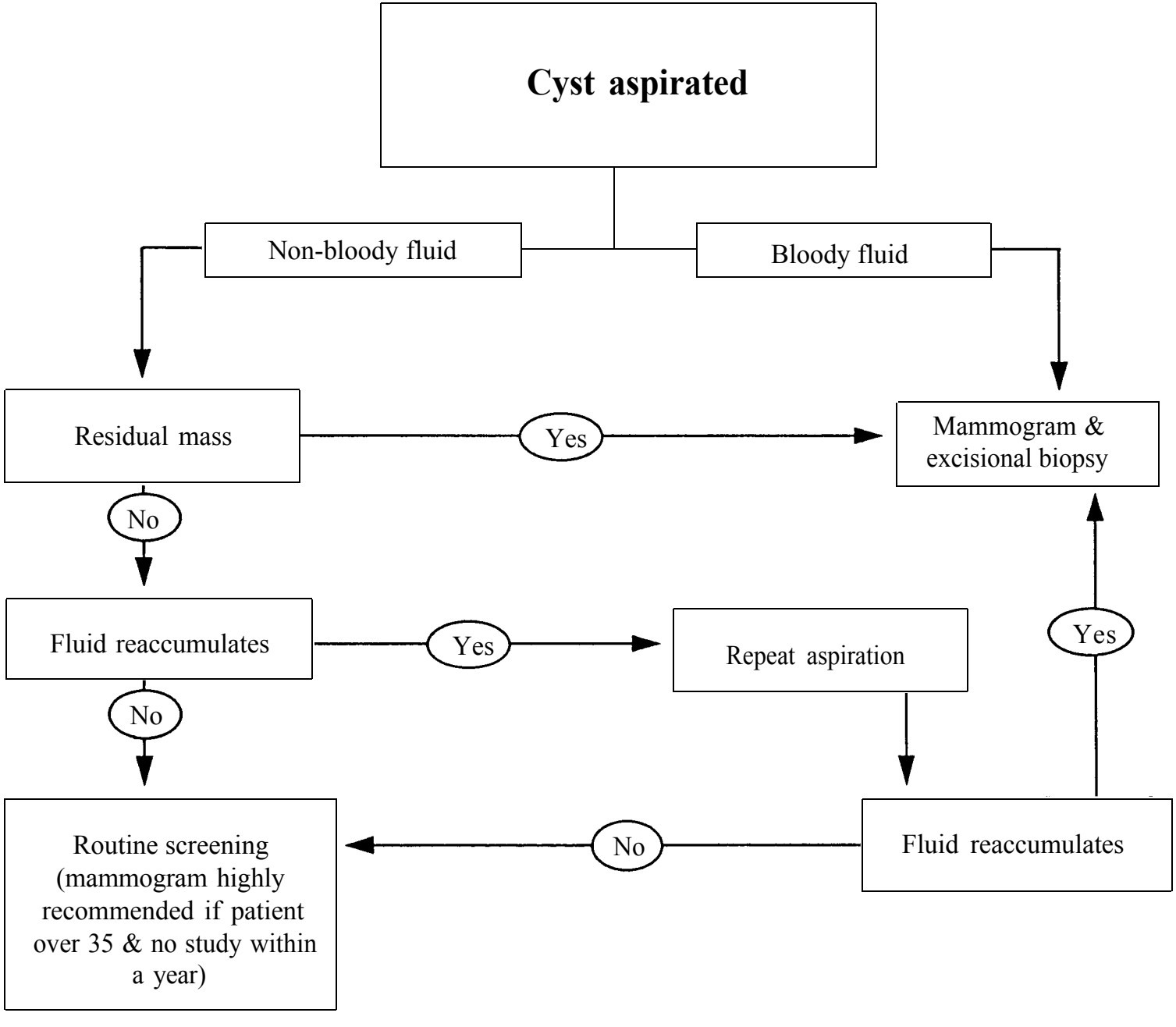
- fine needle aspirate (FNA)
- needle biopsy
- stereotactic needle biopsy
- excisional biopsy
- incisional biopsy
- needle localized biopsy



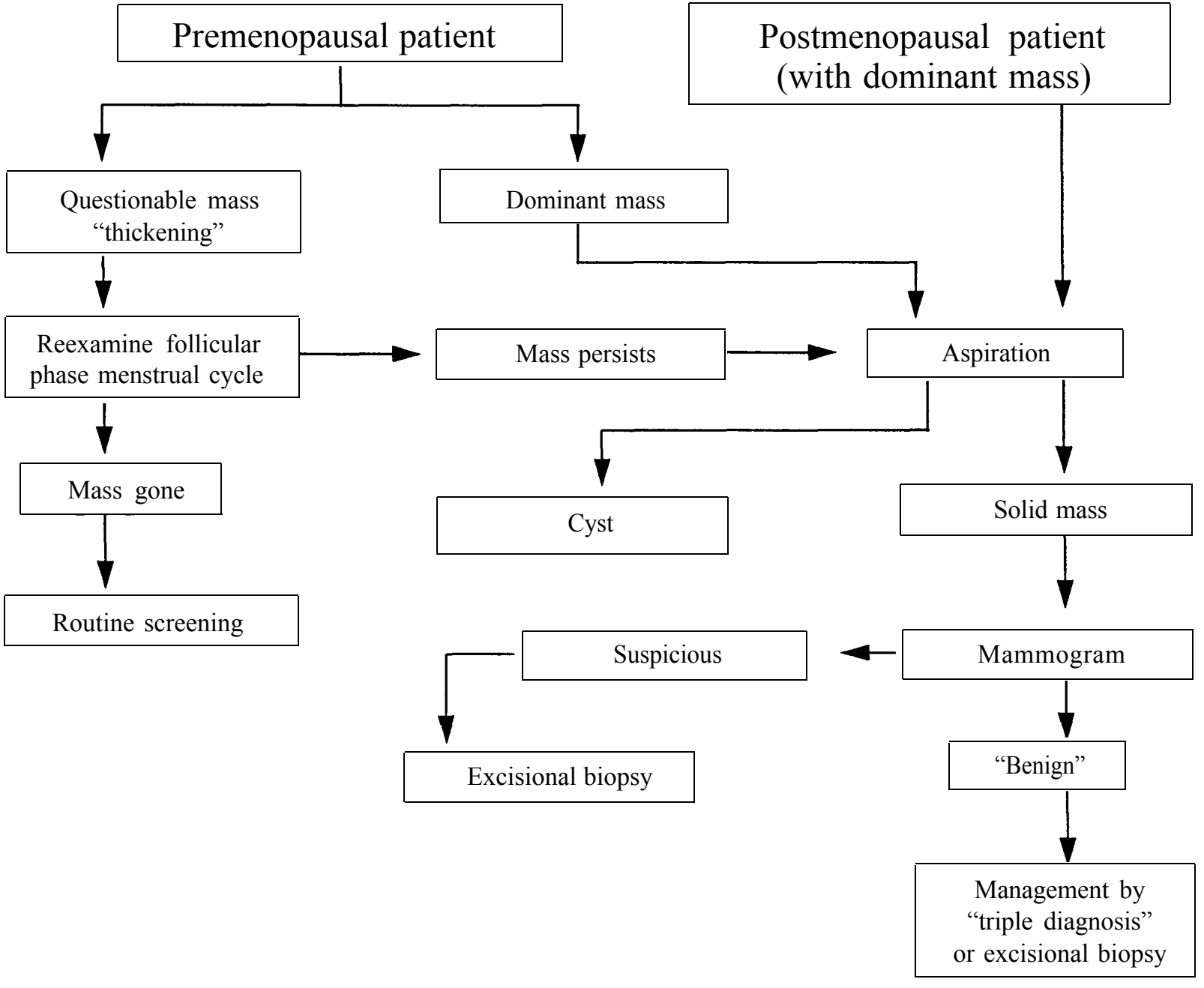
Approaches to abnormalities detected by mammogram



The "triple diagnosis technique"



Management of a breast cyst



Approach to a palpable breast mass

Systemic Therapy for Early Breast Cancer

Hormone Therapy

Tamoxifen

Chemotherapy

Combination of: Cytoxan (Cyclophosphamide, C)
Methotrexate (M)
5-Fluorouracil (5-FU, F)
Adriamycin (Doxorubicin, A)

Typical Systemic Adjuvant Chemotherapy

CMF
given every 3 weeks by vein, 6 times

AC
given every 3 weeks by vein, 4 times

Usual side effects during treatment

1. nausea/vomiting
2. fatigue
3. low blood counts
4. hair loss

Staging of Breast Cancer
Distant Metastasis (M)

M0	No distant metastasis
M1	Distant metastasis (includes spread to ipsilateral supraclavicular nodes)

Staging of Breast Cancer
Stage Grouping

Stage 0	TIS	N0	M0
Stage 1	T1	N0	M0
Stage IIA	T0	N1	M0
	T1	N1	M0
	T2	N0	M0
Stage IIB	T2	N1	M0
	T3	N0	M0
Stage IIIA	T0	N2	M0
	T1	N2	M0
	T2	N2	M0
	T3	N1, N2	M0
Stage IIIB	T4	Any N	M0
	Any T	N3	M0
Stage IV	Any T	Any N	M1

Staging of Breast Cancer
Primary Tumor (T)

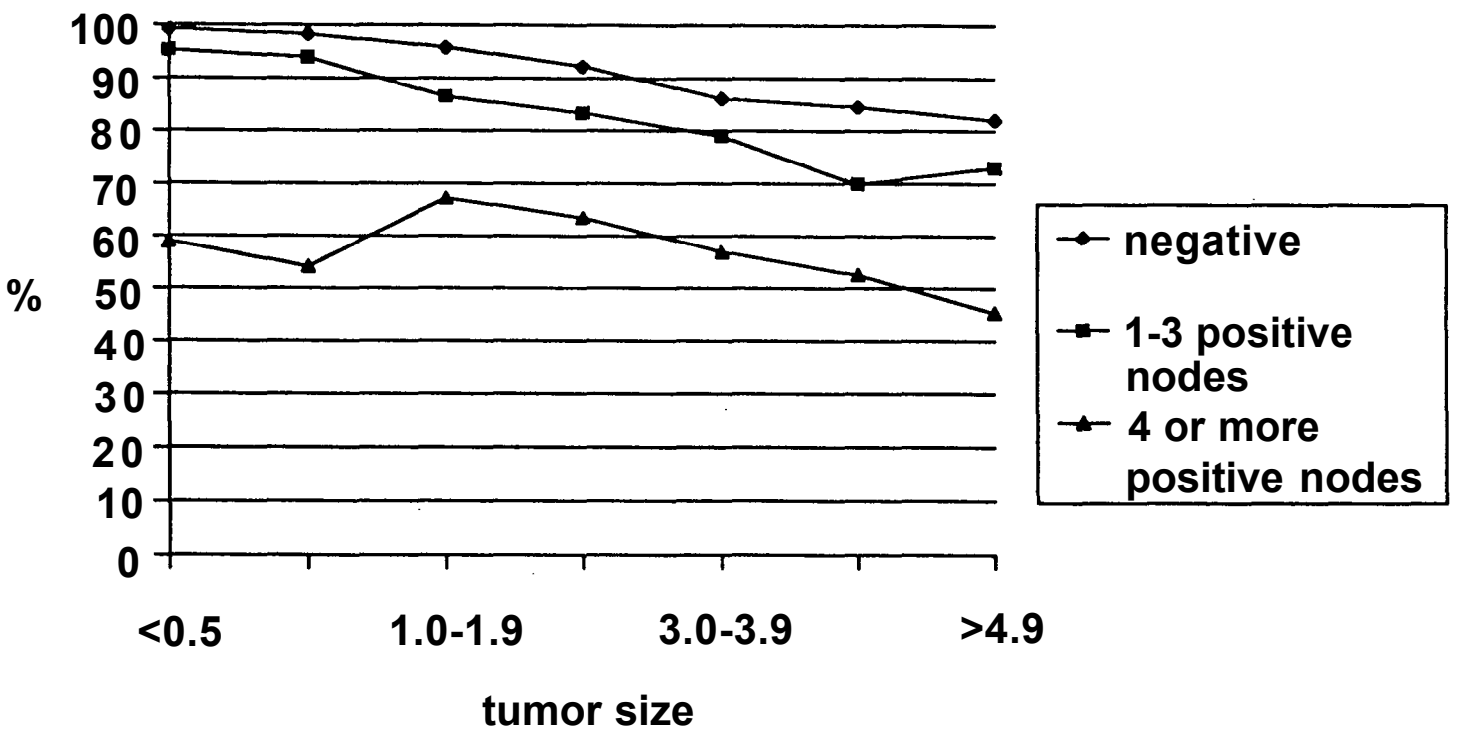
T0	No evidence of primary tumor
Tis	Carcinoma in situ
T1	Tumor $\leq$ 2 cm
T2	Tumor > 2 cm but $\leq$ 5 cm
T3	Tumor > 5 cm
T4	Extension to chest Wall, inflammation

Staging of Breast Cancer
Regional Lymph Nodes (N)

N0	No tumor in regional lymph nodes
N1	Metastasis to movable ipsilateral nodes
N2	Metastasis to matted or fixed ipsilateral nodes
N3	Metastasis to ipsilateral internal mammary nodes

5 year Disease - Free Survival

by tumor size and number of nodes



Trends in Cancer Survival by Race and Year of Diagnosis, United States, 1960-1992

Site	White					African American				
	Relative 5-Year Survival Rate (Percent)					Relative 5-Year Survival Rate (Percent)				
	1960-63	1970-73	1974-76	1980-82	1986-92	1960-63	1970-73	1974-76	1980-82	1986-92
All sites	39	43	50	52	59*	27	31	39	40	44*
Brain	18	20	22	25	29*	19	19	27	31	32
Breast (female)	63	68	75	77	85*	46	51	63	66	70*
Cervix	58	64	69	68	71	47	61	64	61	56*
Colon & rectum	NA	NA	50	55	62*	NA	NA	45	46	53*
Corpus uteri	73	81	89	83	86*	31	44	61	54	56
Esophagus	4	4	5	8	12*	1	4	4	5	8*
Hodgkin's disease	40	67	72	75	82*	NA	NA	69	72	72
Kidney	37	46	52	51	60*	38	44	49	55	55
Larynx	53	62	66	69	68	NA	NA	58	59	52
Leukernia	14	22	35	39	43*	NA	NA	31	33	34
Liver	NA	NA	4	4	7*	NA	NA	1	2	5*
Lung	8	10	12	14	14*	5	7	11	12	11
Melanoma	60	68	80	83	88*	NA	NA	66+	60+	72+
Multiple myeloma	12	19	24	28	28*	NA	NA	27	29	30
Non-Hodgkin's lymphoma	31	41	47	52	52*	NA	NA	48	51	44
Oral	45	43	55	55	55	NA	NA	36	31	33
Ovary	32	36	36	39	46*	32	32	40	39	40
Pancreas	1	2	3	3	4*	1	2	3	5	5*
Prostate	50	63	68	75	89*	35	55	58	65	73*
Stomach	11	13	15	16	19*	8	13	17	19	20
Testis	63	72	79	92	95*	NA	NA	76+	90+	86+
Thyroid gland	83	86	92	94	96*	NA	NA	88	95	90
Urinary bladder	53	61	74	79	82*	24	36	47	59	60*

Note: All sites category excludes basal and squamous cell skin cancers and in situ carcinomas except bladder.
*The difference in rates between 1974-76 and 1986-92 is statistically significant ($p < 0.05$).
+The standard error of the survival rate is greater than 5 percentage points.
NA = not available.
Data source: End Results Group, 1960-1973; NCI Surveillance, Epidemiology, and End Results Program, 1996.

physician. Melanomas often start as small, mole-like growths that increase in size and change color. A simple **ABCD** rule outlines the warning signals of melanoma: **A** is for asymmetry. One half of the mole does not match the other half. **B** is for border irregularity. The edges are ragged, notched, or blurred. **C** is for color. The pigmentation is not uniform or intensely black. **D** is for diameter greater than 6 millimeters. Any sudden or progressive increase in size should be of particular concern.

Treatment: There are five methods of treatment for basal cell cancer and squamous cell cancer: surgery (used in 90% of cases), radiation therapy, electrodessication (tissue destruction by heat), cryosurgery (tissue destruction by freezing) and laser therapy for early skin cancer. For malignant melanoma, the primary growth must be adequately excised, and it may be necessary to remove nearby lymph nodes. Removal and microscopic examination of all suspicious moles is essential. Advanced cases of melanoma are treated according to the characteristics of the case.

Survival: For basal cell or squamous cell cancers, cure is highly likely if detected and treated early. Malignant melanoma can spread to other parts of the body quickly; however, when detected in its earliest stages, and with proper treatment, it is highly curable. The 5-year relative survival rate for patients with malignant melanoma is 87%. For localized malignant melanoma, the 5-year relative survival rate is 95%; and rates for regional and distant disease are 61% and 16%, respectively. About 82% of melanomaa are diagnosed at a localized stage.

WHO GETS BREAST CANCER?

Estimated cases and deaths

Excluding cancers of the skin, breast cancer is the most common cancer among women, accounting for one out of every three cancer diagnoses. In 1996, approximately 184,300 new cases of invasive breast cancer are expected to be diagnosed, and 44,300 women are expected to die from this disease (Table 1).[1] Only lung cancer causes more cancer deaths in women.

TABLE 1. ESTIMATED NEW BREASTCANCER CASES IN WOMEN BY AGE, 1996

Age	Estimate*	Percent of Total
20-29	510	0.3%
30-39	8,700	4.7%
40-49	33,400	18.1%
50-59	30,900	16.8%
60-69	40,000	21.7%
70-79	44,700	24.3%
80+	26,000	14.1%
Total	**184,300**	**100.0%**

**Estimates may not add to total due to rounding*
American Cancer Society, Surveillance Research, 1995
Data from SEER, 1995

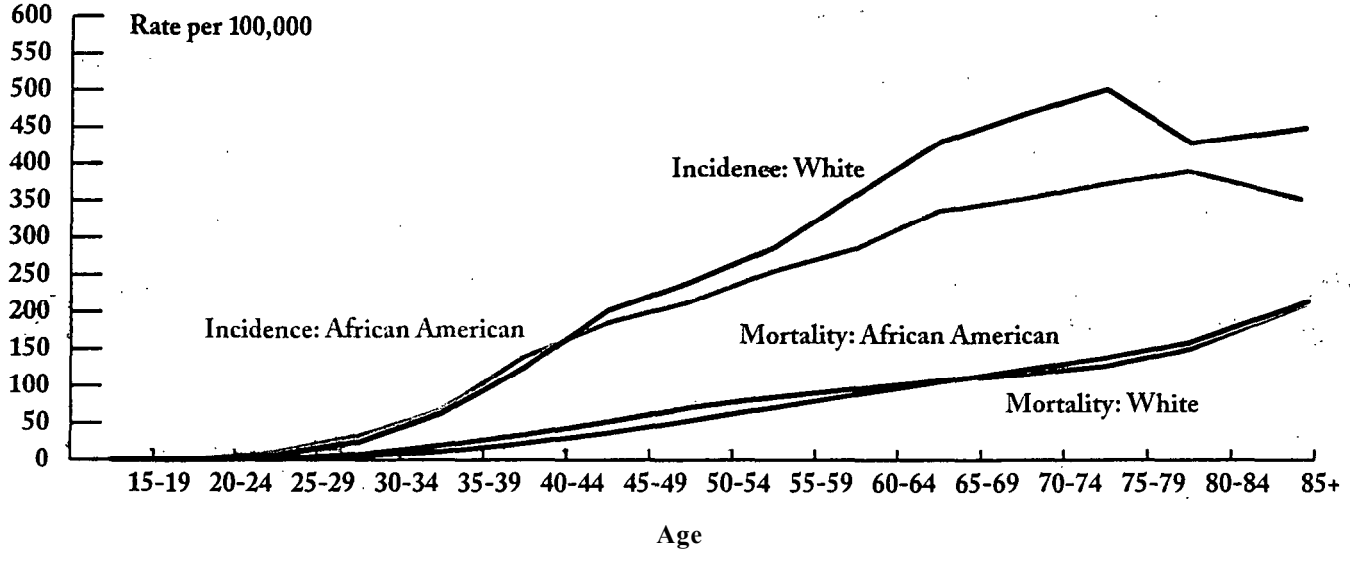
Demographics

Age: The incidence of breast cancer increases with age (Figure 1), and about 77% of women with new diagnoses of breast cancer each year are over the age of 50. Breast cancer is relatively uncommon in younger women, with an incidence rate of one case per 100,000 for women ages 20-24. However, the rate climbs to 25.2 cases for women ages 30-34, 125.4 for women 40-44, and 232.7 for women 50-54.[2] Breast cancer mortality also increases with age. Although heart disease is the leading cause of death in women in the United States, breast cancer is the leading cause of cancer death in women between the ages of 40 and 55.[3]

Race: Over all ages combined, white women are more likely to develop breast cancer than African-American women.[2] The incidence rate for white women is 113.1 cases per 100,000 women and for African-American women, 101.0. Among women younger than 45 years of age, African-American women are more likely to develop breast cancer than white women. Over all ages, African-American women are more likely to die of breast cancer (31.2 per 100,000) than white women (26.0)

Breast cancer incidence and mortality rates vary among other racial and ethnic groups. Between 1977 and 1983,

FIGURE 1. FEMALE BREAST CANCER—AGE–SPECIFIC INCIDENCE AND MORTALITY RATES BY RACE, UNITED STATES, 1988-1992



American Cancer Society, Surveillance Research, 1995
Data from SEER, 1995 and NCHS, 1995

Points About Maintenance

- A mammogram can find an abnormality before it can ever be felt.
- Yearly mammograms allow the physician to monitor any tissue changes that may be taking place.
- A yearly mammogram should be included as a part of your yearly physical for the rest of your life.
- Since breast cancer can't be prevented finding it early could mean the difference between life and death.
- Until medical science can determine the causes of breast cancer, early detection through mammography is the best defense.

RECOMMENDATION: Explain to patients that a correlative breast examination is often done as part of the mammographic examination of a patient with a reported palpable abnormality to make sure that the area of interest is included on the mammogram. The correlative breast examination, performed at the mammography facility, should never be considered a substitute for a complete clinical examination of both breasts, usually performed by the referring health care provider and intended for the detection of unsuspected breast cancer. (C)

In a correlative breast examination, a radiopaque marker (BB) is placed directly over the palpable abnormality to indicate its exact location. The BB directs attention to the area of concern and enables the interpreting physician to determine whether abnormal mammography findings match the location of the palpable abnormality. If the palpable abnormality does not appear on the films, additional views may be taken.

After the mammograms have been done, the interpreting physician may conduct another correlative breast examination to better understand the clinical findings and to properly correlate them with the findings on the mammogram. Subtle changes on the mammogram may have more significance when the clinical findings suggest a possible breast cancer.

Women With Breast Implants

RECOMMENDATION: Women who have had implants for breast augmentation should have mammograms for the detection of nonpalpable cancer at the usual recommended intervals. Although mammography should be performed, it is less effective in detecting cancers in women with implants. (B)

There are now no published data showing an increase in risk of breast cancer among women with implants.

RECOMMENDATION: Mammography of women with breast implants should always be considered diagnostic mammography, even if women are asymptomatic. Diagnostic mammography of women with implants requires special handling and positioning: four views of each breast, rather than two, should be taken whenever possible. (B)

Although unsuspected breast cancer can be detected on mammograms of women with implants, mammography is more difficult to perform. Mammography has not been proven useful for breast cancer detection when implants have been used for breast reconstruction after total mastectomy; regular CBE should be performed in these cases.

Mammography of asymptomatic women with breast implants should include both implant-included and implant-displaced views whenever possible. In the implant-displaced views, the radiologic technologist manually displaces the implant toward the chest wall while bringing breast tissue forward so'that it can be adequatel compressed. This maneuver in an improved image of the anterior breast tissue.

Views, Compression, and Positioning

RECOMMENDATION: Be aware that screening mammography consists of two standard views of each breast: the mediolateral oblique and craniocaudal views. For the workup of a clinical or mammographic abnormality (diagnostic mammography), a large number of additional techniques are available. (B)

The primary goal of positioning for screening mammography is to show all of the breast tissue on the two standard views. The most commonly used additional views for diagnostic mammography are "spot compression" and "magnification," which are intended to better define a possible mammographic abnormality.

Spot compression involves the use of a smaller compression device to optimize compression over a local area of concern and to displace overlying tissues away from the area of concem. Magnification is used to improve the visibility of the details of the margins of a mass or to better see and characterize microcalcifications.

RECOMMENDATION: Be aware that positioning of the breast for mammography has undergone considerable changes in recent years and that positionir be done by experienced technologists who have been trained in the most recent advances in mammography

RECOMMENDATION: Inf women that breast comp necessary for good-quality mammography and lower x-ray dose needed. Infor that compression may b uncomfortable and that should tell the radiological technologist if it is painf

Proper compression is for high-quality mammog Compression involves pre breast between a clear-pla movable plate (the compr device) and the platform l the film during mammogr Compression:

- Reduces breast thickne: improving the visualiza structures within the br may be indicative of br cancer, enhancing imag (by decreasing scattered radiation), and lowering dose.
- Immobilizes the breast, preventing motion that the image of breast stn

APPENDIX E

CHE Forms

ROSE
Robeson County Outreach Screening & Education Project

HEALTH EDUCATION

Participant Contact Documentation / Encounter Form

VISIT 1

Participant Name _____ ID Number _____

Telephone Number _____ Race _____

RECORD OF CALLS AND CONTACTS

DAY	DATE	TIME	COMMENTS	CONTACT TYPE	CONTACT CODE	CHE

CONTACT CODES

01 Participant Not Home
02 No one Home
03 Busy/Call Back
04 Refused to Conduct Visit
05 Refused to Schedule Visit
06 Broken Appointment, Rescheduled
07 Broken Appointment, Not Rescheduled
08 Call Back, Left Message
09 Appointment Scheduled
10 Completed Visit
11 Completed Telephone Contact
99 OTHER

CONTACT TYPE - **T** = Telephone, **I/P** = In Person, **M** = Mail

General Comments:

Questions asked by Participant:

Barriers Reported:

Materials / Information Given to Participant (check all that apply):

_____NCI Bookmark _____Keeping the Circle Brochure _____Telephone Card
_____Wise Woman Brochure _____Call a Ride Brochure _____NCI Booklet
_____Other (specify)

Has the participant obtained a **Mammogram** since our last contact? YES_____NO_____

If YES, When?_____Where?_____

Ask her to describe the experience_____

If NO, Why Not?_____

Did you offer to assist participant in scheduling a mammogram?

YES_____What type_____

NO_____Why Not_____

Mammogram Appointment Scheduled: YES____NO_____ DATE _____

WHERE_____TIME_____

COMMENTS:_____

Has the participant obtained a **CBE** since our last contact? YES______ NO_______ If YES,

When?________________________________ Where?____

Ask her to describe the experience____

____

(If NO, offer to assist her in scheduling a CBE with her physician)

Clinical Breast Exam Appointment Scheduled: YES_____ NO____DATE_________________________

WHERE____TIME_______________________

COMMENTS:____

____

~~~~~~

Next Contact / Visit Scheduled: YES______ NO________Why/WhyNot?______________________

____

When______________________________________Time____

(record date)

~~~~~~

CHE's Rating of Rapport with Participant:

POOR ☐1 FAIR ☐2 GOOD ☐3 EXCELLENT ☐4 UNABLE TO DETERMINE ☐5

CHE's Rating of Participant's Understanding of Materials/Information:

POOR ☐1 FAIR ☐2 GOOD ☐3 EXCELLENT ☐4 UNABLE TO DETERMINE ☐5

CHE's Rating of Participant's Overall Interest in Breast Cancer Screening:

POOR ☐1 FAIR ☐2 GOOD ☐3 EXCELLENT ☐4 UNABLE TO DETERMINE ☐5

COMMENTS:

____

____

____

LENGTH OF VISIT:

CHE Signature____**Date**_____________________________

ROSE
Robeson County Outreach Screening & Education Projcct

HEALTH EDUCATION

Participant Contact Documentation / Encounter Form

VISIT 2

Participant Name_____ ID Number_____

Telephone Number_____ Race_____

RECORD OF CALLS AND CONTACTS

DAY	DATE	TIME	COMMENTS	CONTACT TYPE	CONTACT CODE	CHE

CONTACT CODES

01 Participant Not Home
02 No one Home
03 Busy/Call Back
04 Refused to Conduct Visit
05 Refused to Schedule Visit
06 Broken Appointment, Rescheduled
07 Broken Appointment, Not Rescheduled
08 Call Back, Left Message
09 Appointment Scheduled
10 Completed Visit
11 Completed Telephone Contact
99 OTHER

CONTACT TYPE - **T** = Telephone, **I/P** = In Person, **M** = Mail

General Comments:

Questions Asked by Participant:

Barriers Reported:

Materials / Information Given to Participant (check all that apply):

_____Breast Self Exam Brochure _____Down Home Healthy Cookbook ____Wise Woman Brochure
_____Your Best Body _____Eat 5 Fruits and Vegitables a Day ____Call A Ride Brochure
_____Other (specify) _____

Has the participant obtained a **Mammogram** since our last contact? YES_____NO_____

If YES, When?_____Where?_____

Ask her to describe the experience_____

If NO, Why Not?_____

Did you offer to assist participant in scheduling a mammogram? YES_____ What Type_____

NO_____Why Not_____

Mammogram Appointment Scheduled: YES____NO_____ DATE_____

WHERE_____TIME _____

COMMENTS:_____

Has the participant obtained a **CBE** since our last contact? YES______NO_______If YES,

When?________________________________Where?____

Ask her to describe the experience____

____

(If NO, offer to assist her in scheduling a CBE with her physician)

Clinical Breast Exam Appointment Scheduled: YES_____ NO____DATE________________________

WHERE____TIME______________________

COMMENTS:____

____

~~~~~~

Next Contact / Visit Scheduled: YES______ NO________Why/Why Not?________________________

____

When ______________________________________Time____
(record date)

BSE Training conducted YES____ NO______COMMENTS____

~~~~~~

CHE's Rating of Rapport with Participant:

POOR ☐ 1 FAIR ☐ 2 GOOD ☐ 3 EXCELLENT ☐ 4 UNABLE TO DETERMINE ☐ 5

CHE's Rating of Participant's Understanding of Materials/Information:

POOR ☐ 1 FAIR ☐ 2 GOOD ☐ 3 EXCELLENT ☐ 4 UNABLE TO DETERMINE ☐ 5

CHE's Rating of Participant's Overall Interest in Breast Cancer Screening:

POOR ☐ 1 FAIR ☐ 2 GOOD ☐ 3 EXCELLENT ☐ 4 UNABLE TO DETERMINE ☐ 5

COMMENTS:

____

____

____

LENGTH OF VISIT:

CHE Signature____**Date**________________________________

ROSE
Robeson County Outreach Screening & Education Project

HEALTH EDUCATION

Participant Contact Documentation / Encounter Form

VISIT 3

Participant Name_____ ID Number_____

Telephone Number_____ Race_____

RECORD OF CALLS AND CONTACTS

DAY	DATE	TIME	COMMENTS	CONTACT TYPE	CONTACT CODE	CHE

CONTACT CODES

01 Participant Not Home
02 No one Home
03 Busy/Call Back
04 Refused to Conduct Visit
05 Refused to Schedule Visit
06 Broken Appointment, Rescheduled
07 Broken Appointment, Not Rescheduled
08 Call Back, Left Message
09 Appointment Scheduled
10 Completed Visit
11 Completed Telephone Contact
99 OTHER

CONTACT TYPE - **T** = Telephone, **I/P** = In Person, **M** = Mail

General Comments:

Questions Asked by Participant:

Barriers Reported:

Materials / Information Given to Participant:

Has the participant obtained a **Mammogram** since our last contact? YES_____NO_____

If YES, When?_____Where?_____

Ask her to describe the experience_____

If NO, Why Not?_____

Did you offer to assist participant. YES_____What type?_____
in scheduling a mammogram?

NO_____Why Not?_____

Mammogram Appointment Scheduled: YES____NO_____ DATE_____

WHERE_____TIME_____

COMMENTS:_____

Has the participant obtained a **CBE** since our last contact? YES______NO_______If YES,

When?_______________________________ Where?____

Ask her to describe the experience ____

____

(If NO, offer to assist her in scheduling a CBE with her physician)

Clinical Breast Exam Appointment Scheduled: YES_____ NO____DATE_______________________

WHERE____TIME_____________________

COMMENTS:____

____

~~~~~~

Next Contact / Visit Scheduled: YES______ NO ________Why/Why Not?______________________

____

When____________________________________Time____
(record date)

BSE Training conducted YES____NO______COMMENTS___________________________________

~~~~~~

CHE's Rating of Rapport with Participant:

POOR ☐ 1 FAIR ☐ 2 GOOD ☐ 3 EXCELLENT ☐ 4 UNABLE TO DETERMINE ☐ 5

CHE's Rating of Participant's Understanding of Materials/Information:

POOR ☐ 1 FAIR ☐ 2 GOOD ☐ 3 EXCELLENT ☐ 4 UNABLE TO DETERMINE ☐ 5

CHE's Rating of Participant's Overall Interest in Breast Cancer Screening:

POOR ☐ 1 FAIR ☐ 2 GOOD ☐ 3 EXCELLENT ☐ 4 UNABLE TO DETERMINE ☐ 5

COMMENTS:

____

____

LENGTH OF VISIT:

ROSE
Robeson County
Outreach
Screening &
Education Project

HEALTH EDUCATION

Non-Participant

Contact Documentation / Encounter Form

Name_____

Telephone Number_____ Race_____

RECORD OF CALLS AND CONTACTS

DAY	DATE	TIME	COMMENTS	CONTACT TYPE	CHE

CONTACT TYPE - **T** = Telephone, **I/P** = In Person, **M** = Mail

CONTACT LOCATION_____

_____

_____

How Did the Individual Hear ahout ROSE?

Read Something ☐ Saw Something ☐ Heard Something ☐

Is in Comparison Group ☐ Friend/Relative Told Her ☐

☐ Other: (Specify)_____

COMMENTS:_____

_____

_____

Questions Asked by Individual:

Answers Given by CHE:

Questions Asked by Individual:

Answers Given by CHE:

Other Items Discussed:

Materials / Information Given to Participant:

Follow-up activities?:

COMMENTS:

LENGTH OF CALL / CONTACT:

CHE SIGNATURE DATE

ROSE
Robeson County Outreach Screening & Education Project

ID # _____

ROSE
HEALTH EDUCATION BARRIER ASSESSMENT

Participant: _____ Date: _____
CHE: _____

1. Have you ever had a mammogram?
(Circle the appropriate answer)

NO	1	GO TO 3
YES	2	
NA	3	

2. How long has it been since your last mammogram?
(If participant doesn't know, probe to determine a time frame to determine most recent date of mammography.)

LESS THAN 6 MONTHS	1	(Stop Here)
6 MONTHS TO 1 YEAR	2	(Stop Here)
BETWEEN 1 & 2 YEARS	3	GO TO 4
BETWEEN 2 & 3 YEARS	4	GO TO 4
BETWEEN 3 & 4 YEARS	5	GO TO 4
OVER 4 YEARS	6	GO TO 4

3. What (from the following list) are the most important reasons you have never had a mammogram? Please answer yes or no to the following statements.

(READ STATEMENTS A-K. PLACE A CHECK INSIDE THE BOX IF THE PARTICIPANT ANSWERS YES.)

A. ☐ I don't have any **symptoms.**

A	D	
☐	☐	I feel okay, so I don't need a mammogram.
☐	☐	I've not gotten cancer in all this time, so why worry about it.
☐	☐	Other

ID # _____

B. ☐ **Transportation** Problems

A	D	
☐	☐	I don't drive, and finding someone else to take me is too much trouble.
☐	☐	I would have to go too far to get a mammogram.

C. ☐ **Cost**

A	D	
☐	☐	I can only afford to see the doctor when I really need to and not just for a test.
☐	☐	I don't have insurance to cover that.
☐	☐	I would lose money if I took the time off work.

D. ☐ **Harmful Side Effects**

A	D	
☐	☐	I am afraid of the radiation from the mammogram.
☐	☐	A mammogram is just too painful.
☐	☐	I don't want to get bruised.

E. ☐ **Fellings of Doom or Hopelessness**

A	D	
☐	☐	If I had breast cancer, I'd rather not know.
☐	☐	If I have cancer, it is God's will.

F. ☐ **No Referral Form Physician**

A	D	
☐	☐	My doctor hasn't told me I need a mammogram.
☐	☐	I've never seen or heard anything that said I needed a mammogram.

ID # _____

G. ☐ **Having a mammogram is embarrassing**

A	D	
☐	☐	It's too embarrassing to have a mammogram.
☐	☐	I'm too uncomfortable being undressed in front of someone else.

H. ☐ **The mammogram experience makes me nervous and afraid (fear/anxiety)**

A	D	
☐	☐	I get too nervous at the thought of maybe learning that I have cancer.
☐	☐	The mammography experience scares me and makes me nervous.

I. ☐ **I don't want to know (denial)**

A	D	
☐	☐	If I have cancer, I'd rather not know.
☐	☐	I'm afraid that they will find cancer if they go looking for it.

J. ☐ **Feelings of Being Labeled or Stigmatized**

A	D	
☐	☐	If they find that I have breast cancer, people may treat me differently.
☐	☐	People with cancer shouldn't be around others -- they may pass it on.

K. ☐ **Negative Input from Family/Friends**

A	D	
☐	☐	Someone close to me had an awful experience.
☐	☐	My friend or family member said I don't need one
☐	☐	My husband or boyfriend doesn't want me to have one.

3a. For each of these reasons you just answered yes to, please tell me if you agree (A) or disagree (D) to each of the following statements.

(READ THE SENTENCES LISTED ONLY UNDER THE CHECKED ITEMS A-K.)

4. What is the one most important reason that has kept you from getting a recent mammogram? **(DO NOT READ LIST; CHECK CLOSEST APPORIATE ANSWER [PROBE ONLY ONCE])**

☐	I don't have any symptoms.
☐	Transportation problems.
☐	Cost.
☐	Harmful Side Effects.
☐	Doomed.
☐	No Referral From Physician.
☐	Having a mammogram is embarrassing.
☐	The mammogram experience makes me nervous and afraid (fear/anxiety).
☐	I don't want to know (denial).
☐	Labeled.
☐	Negative Input from Family/Friends.
☐	Other _____ *(specify)*

5. Are there one or two more reasons that I have not mentioned that has kept you from getting a mammogram?

_____

_____

(REFER TO BARRIER PROMPT CARD IF NECESSARY)

ROSE
Robeson County Outreach Screening & Education Progject

ROSE

PARTICIPANT STAGING FORM

NAME_____ ID Number_____

ADDRESS_____

_____

AGE_____ TELEPHONE NUMBER_____

1. Have you ever had a mammogram?

   _____ YES **GO TO 3**
   _____ NO

2. Are you planning to have one in the next year?

   _____ YES → **Contemplation** ↘
   _____ NO → **Precontemplation** → **END** **(GO TO 8)**
   _____ DK → **Precontemplation** ↗

3. When was your last Mammogram?

   MONTH_____YEAR_____

   If
   _____≤ 14 months - **GO TO 5**
   _____> 14 months ago

4. Are you planning to have a mammogram in the next year?

   _____ YES → **Contemplation** ↘
   _____ NO → **Relapse** → **END** **(GO TO 8)**
   _____ DK → **Relapse** ↗

5. When was your last mammogram before the last one (mentioned in Q. #3)?

   MONTH_____YEAR_____

   If
   _____≤ 14 months - **GO TO 7**
   _____> 14 months ago

6. Are you planning to have a mammogram in the coming year?

_____ YES → **Action**
_____ NO → **Relapse**
_____ DK → **Relapse**

7. Are you planning to have a mammogram in the coming year?

_____ YES → **Maintenance**
_____ NO → **Relapse**
_____ DK → **Relapse**

8.a Type of staging card mailed _____

b. Date staging card mailed _____

Completed By _____

Date _____

WEEKLY INTERVENTION PROGRESS REPORT

Week of _____
(Sunday - Saturday date)

INTERVENTION	INTERVENTION COMPLETED **THIS WEEK**	**NEXT WEEK'S** INTERVENTION LOAD	REFUSALS RESCHEDULES (note type)	
				TOTAL
Appointment call for visit one				
VISIT 1				
Appointment call for visit two				
VISIT - 2				
ROSE TIDBIT CALL 1				
ROSE Staging Pamphlet mailed				
ROSE TIDBIT CALL 2				
Appointment call for visit three				
VISIT - 3				
Final Check to prepare closeout				
Other Contacts				
VISIT TOTALS				
NEW PARTICIPANTS ASSIGNED				

COMMENTS _____

_____

_____

CHE Initials _____ **Today's Date** _____

ROSE
Robeson County Outreach Screening & Education Project

ROSE STAFF IDENTIFICATION INFORMATION

Name: _____ Date: _____

Address: _____

_____

Telephone Number(s): _____

Social Security Number: _____

First Car	Second Car
Make:	Make:
Model:	Model:
Color:	Color:
Year:	Year:
License Plate Number:	License Plate Number:

IN CASE OF EMERGENCY, CONTACT:

First Person:

Name: _____ (_____)
relation to staff person

Address: _____

Telephone Number: _____

Second Person:

Name: _____ (_____)
relation to staff person

Address: _____

Telephone Number: _____

ROSE
Robeson County
Outreach
Screening &
Education Project

DATA COLLECTION AGREEMENT

I, _____, agree to provide field data collection services for Wake Forest University School of Medicine in connection with the **ROSE** Project.

- I agree to provide services within the guidelines and specifications for project data collection activities provided by **ROSE.**
- **I agree to provide complete and <u>true</u> information within the guidelines and specifications for project data Collection activities provided by ROSE. I am aware that my completed work will be verified on a regular basis by ROSE staff members.**
- I agree to treat as <u>confidential</u> all information secured during interviews or obtained in any project- related way during the period I am providing services to Wake Forest University School of Medicine.
- I shall at all times recognize and protect the confidentiality of all information secured while providing my services throughout the conduct of this research project;
- I am aware that the survey instruments completed form the basis from which the analysis will be drawn, and therefore agree that all work for which I submit time and expense reports will be of high quality and in accordance with project specifications; and
- I fully agree to conduct myself at all times in a manner that will obtain the respect and confidence of all individuals from whom data will be collected. I will not betray this confidence by divulging information obtained to anyone other than authorized representatives of the **ROSE** Project.
- Violation of these rules and regulations will result in immediate termination of employment.

Dated at _____
(City/Town) *(State)*

this _____ day of _____ 1998

_____
(Employee)

_____
(For **ROSE**)

ALL TRAVEL EXPENSE VOUCHERS ARE SUBJECT TO VERIFICATICON, INCLUDING THIRD PARTY CONFIRMATION PROCEDURES.

TRAVEL EXPENSE VOUCHER

The Bowman Gray School of Medicine of Wake Forest University

(Instructions on Reverse Side)

Departmet/Section: _____ Form Completion Date: _____

Traveler: _____ Destination: _____

Telephone Extension: _____

Date of Travel	Transportation				Hotel	Meals			Registration Fees	**NON ALLOWABLE COSTS**	Miscellaneous	
	Airfare	Personal Vehicle Rate ¢ # of Miles	Total Cost	Other Transportation Cost	Single Rate and Tax	Breakfast	Lunch	Dinner			Amount	Description
TOTALS												

Indicate Complete Account Number(s):

|_|_|_|_|_|_|_|_|_|_|_|_|_|_|_|_| $_____.

|_|_|_|_|_|_|_|_|_|_|_|_|_|_|_|_| $_____.

|_|_|_|_|_|_|_|_|_|_|_|_|_|_|_|_| $_____.

|_|_|_|_|_|_|_|_|_|_|_|_|_|_|_|_| $_____.

Total Travel Expenses $_____.

Total Travel Expenses $_____.

LESS:

Cash Advance $_____.

Air Fare Charged to School $_____.

Advance Room Deposit Paid by School $_____.

Advance Registration Fee Paid by School $_____.

Total School Expenses $_____.

Due Employee $_____.

Due School $_____.

I certify that the above charges are true, just and were incurred for school related business and no part of these expenses have been or will be reimbursed by a Third Party (External Organization or Individual). I further certify that Non-Allowable Costs, as defined by Federal guidelines, have been listed in the **NON- ALLOWABLE COSTS** column.

_____

Signature of Traveler (Sign in **ALL** Cases)

I, hereby approve the above expenses:

_____

Signature of Department/Section Head

Yellow-Controller's Office **Blue-Traveler's Copy**

Revised 1/93

ROSE
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Education Project

WEEKLY TRAVEL LOG

Name: _____

Social Security Number: _____

For Week of_____

DATE	DESTINATION	MILES	REASON FOR TRIP

TOTAL MILES: _____ **DATE:** _____

BGSM
TIME & ATTENDANCE CARD

Dept No. 194

Print Name
EMPLOYEE NAME (PRINT)

Sign Name Date
EMPLOYEE SIGNATURE DATE

EMPLOYEE ID NO.

0									
0	0	0	0	0	0	0	0	0	0
1	1	1	1	1	1	1	1	1	1
2	2	2	2	2	2	2	2	2	2
3	3	3	3	3	3	3	3	3	3
4	4	4	4	4	4	4	4	4	4
5	5	5	5	5	5	5	5	5	5
6	6	6	6	6	6	6	6	6	6
7	7	7	7	7	7	7	7	7	7
8	8	8	8	8	8	8	8	8	8
9	9	9	9	9	9	9	9	9	9

WEEK STARTING	
MON	DAY
SUN	DAY

SUNDAY	
CAT NO.	NO. OF HOURS

MONDAY			TUESDAY		
CAT NO.		NO. OF HOURS	CAT NO.		NO. OF HOURS
		0			0

WEDNESDAY			THURSDAY		
CAT NO.		NO. OF HOURS	CAT NO.		NO. OF HOURS
		0			0

FRIDAY			SATURDAY		
CAT NO.		NO. OF HOURS	CAT NO.		NO. OF HOURS
		0			

SUPERVISOR DATE
SUPERVISOR SIGNATURE DATE

PET

Production, Expense, and Time Report Form

Interviewer/CHE ID # _____			**Week Beginning Sunday,** _____						
A.	B.	C.	D.	E. HOURS WORKED					F. EXPENSES
TOTAL HOURS WORKED	# of Completed Intenrviews/Visits	# of Attempted Interviews/Vsits	Day of The Week	1. Interviewing or Educating Time each day	2. Contacting/ Locating	3. Editing	4. Conference/ Meeting	5. Other	Miles Driven
			SUN	am					
				pm					
			MON	am					
				pm					
			TUE	am					
				pm					
			WED	am					
				pm					
			THUR	am					
				pm					
			FRI	am					
				pm					
			SAT	am					
				pm					
			TOTALS						

INTERVIEWER / *CHE* **NAME** _____

INTERVIEWER / *CHE* **ADDRESS** _____

TELEPHONE # _____ **Please remember to complete the following forms: 1) Travel Log Form; 2) Comments Form (if necessary)**

INTERVIEWER / *CHE* **SIGNATURE** _____ **DATE** _____

2/8/97

HOURS WORKED _____ MILES DRIVEN _____ SUPERVISOR'S INTIALS _____ DATE _____

WORK STATUS REPORT

WEEK OF _____

INTERVIEWER _____

TEMPORARY CODES	
CODES	**Number In Progress**
01 - No action taken / Pending	
02 - No eligible person home	
03 - No one home	
04 - Temporary refusal	
05 - Busy	
06 - Call Back	
07 - Broken appointment, rescheduled	
08 - Broken appointment, not rescheduled	
09 - Partial interview	
TOTALS	

FINAL CODES	
CODES	**Number Completed**
11- Unable to reach household after repeated attempts	
13- Mentally / Physically Unable to complete interview	
14- Language/ Heaiing Banier	
15- Vacant	
16- Deceased	
17- Respondent moved from area	
99- Other	
12- FINAL REFUSAL	
10- COMPLETED INTERVIEWS	
TOTALS	

APPENDIX F

CHE ID Letter

Robeson Health Care
CORPORATION

Dear _____:

This letter and identification badge serve to identify _____, an authorized community health educator for the Robeson County Outreach Screening and Education (ROSE) Project. This important medical study is being directed by the Robeson Health Care Corporation (RHCC) and Wake Forest University School of Medicine, and is sponsored by the National Institutes of Health.

_____, an authorized representative of the ROSE Project, is sworn to keep any information you volunteer completely confidential.

For further verification feel free to call Janice Strickland, Assistant Project Manager, at (910) 739-9511 or Cathy Tatum, Project Manager, at (336) 716-6717.

Thank you for your participation in this project.

Sincerely,

Dennis Stuart, M.D.
Chief Medical Officer
Robeson Health Care Corporation

APPENDIX G

CHE Quick Tips

CHE Quick Tips

- **When making your initial appointment phone call do no use the words "breast cancer. Instead tell the participant that you will be providing information that" encourages healthy living".**

- **Complete all CHE Encounter Forms as soon as possible after the visit is completed, while the visit is still fresh in your mind. Use your hand held tape recorder to record important information about the visit.**

- **As you complete each visit make sure that the major goal was achieved and the participant has a good understanding of that goal.**

- **All ROSE forms should be completed in black ink (unless other wise stated). Please be sure to write so that it is easy to read. Please print if possible.**

- **Please be sure to leave a completed door hanger on the doors when you find no one home.**

- **Donot accept the assignment of participants that you are personally familiar with, related to or are uncomfortable with. When this situation occurs please notify your supervisor.**

- **Document everything!!!! We want to know details.**

- **Be prepared to discuss at weekly staff meetings all completed work, all work in progress, calls made etc....**

- **Always prepare participant packets the day prior to your visit to make sure that you have everything that you need.**