Part I: An Implementation Guide For



A Culturally Competent, Community-Based Cancer Education Program For African American Women Copyright © 1996, 1998, 2000, 2004 The Board of Trustees of the University of Arkansas.

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- Arkansas Cancer Research Center at the University of Arkansas for Medical Sciences
- Arkansas Breast and Cervical Cancer Control Program at the Arkansas Department of Health
- Avon Breast Health Access Fund
- Central Arkansas Radiation Therapy Institute
- Delta Health Education Center
- Health Education Program at the University of Arkansas at Little Rock
- National Black Leadership Initiative on Cancer
- Susan G. Komen Breast Cancer Foundation

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- National Cancer Institute

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Original Witness Project® sites included Bridgeport, Connecticut; Hattiesburg, Mississippi; Bloomington/Normal, Illinois; Lon Branch, New Jersey, and Wichita, Kansas. These sites purchased the first edition of our Implementation Guide and began their own programs after signing a Trademark License Copyright Agreement to use our logo and training materials. In 1997, these sites agreed to become our partners and form a national coalition.

Other sites have heard about and requested our training materials. These sites have signed a trademark license copyright agreement and Memorandum of Agreement and are using our logo and training materials.

In response to our CDC grant for expansion of The Witness Project® nationally, in 1998 we began selecting **pilot sites** for the Replication and Dissemination (R&D) of The Witness Project®.

iv Acknowledgments

> Pilot sites have been testing the effectiveness of replication and implementation of The Witness Project® model across the nation. There are currently twenty-five Witness Project® in seventeen states across the nation.

> In some states, The Witness Project® is operated under the auspices of the hospital and has been included as part of their community outreach programs. Other states have partnered with organizations such as the American Cancer Society and or the Susan G. Komen Breast Cancer Foundation, and conduct their programs out of these offices. National partners have collaborated with churches, sororities, shopping centers, and high schools in planning programs and activities for breast and cervical cancer education and awareness.

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Linda A. Deloney, MA, Editor Arkansas Cancer Research Center University of Arkansas for Medical Sciences **April** 1996

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Memorandum of Agreement

Introduction: This is a legal and binding agreement by and between *The Witness Project*® (WP) on behalf of the University of Arkansas for Medical Sciences, a public institution and instrumentality of the State of Arkansas, having offices at 4301 West Markham Little Rock, AR 72205, and WP sites, all of which, are not for profit organizations, having offices at ________. All WP sites as previously described agree to replicate the WP model in their respective areas for the purpose of increasing screening for the early- detection of breast and cervical cancer among African American women (AAW).

Background: The WP is a culturally competent, community-based cancer education program designed to meet the specific cultural, educational, knowledge and learning style levels of underserved AAW. Created in 1990, this program recruits, trains, and provides resources to African American (AA) breast and cervical cancer survivors to become Witness Role Models (WRMs) and other AAW to become trained as Lay Health Advisors (LHAs). These WRMs and LHAs go as teams to provide culturally appropriate cancer education and empowerment messages for AAW in churches and community groups to encourage and facilitate the practice of breast self-examination (BSE), mammography, clinical breast examination (CBE), pelvic examinations, and Pap test screening.

Purpose: Participating organizations agree to replicate the WP. Participating organizations are expected to establish and maintain WP programs in specific sites nationally and train groups consisting of African American cancer survivors and lay health educators. These groups will inform and provide resources for accessing critical breast and cervical cancer screening services to underserved women, including older women, low-income, uninsured and/or underinsured AAW.

Responsibilities: Under this agreement, WP partners will maintain close collaboration with their local Breast and Cervical Cancer Control Program (BCCCP) service providers, ensure that a referral process is in place that will inform women of available breast and cervical cancer- screening resources, and direct women to these resources. Responsibilities of partners for the duration of the grant are as follows:

- Recruit a project director or coordinator, and potential WRMs and LHAs.
- Complete a Trademark Licensing Copyright Agreement for the time period specified.
- Maintain the following current WP standards:
 - 1. Present information about monthly BSE, annual CBE, annual mammogram beginning at age 40, pelvic exams, and Pap tests at every WP program, and urge participants to practice these preventive health behaviors.
 - 2. Recruit only cancer survivors (preferably breast and cervical cancer) as WRMs.
 - 3. Conduct an 8-hour training curriculum (as outlined in the WP Facilitator Training Manual) for both LHAs and WRMs, regardless of the experience they bring with them.
 - 4. Document that LHAs have observed at least 3 programs before they began presenting program information.
 - 5. Document that LHAs practice giving cancer facts, resources, and teaching BSE (role-play) before actually presenting program information.
 - 6. Establish an agreement with WRMs and LHAs that they present a minimum of 3 programs per year.
 - 7. Have a minimum of 2 WRMs and 1 LHA trained, or 3 WRMs where one survivor serves as a LHA, or 3 WRMs and a staff member to serve as a health educator to teach BSE and cancer facts. These members must be trained before scheduling programs. WP partners (prior to April' 1998) must conduct at least 6 programs a year. WP pilots must conduct at least 3 programs within the first 9 months after the team has been trained.

- 8. Ensure that at least 2 WRMs witness at programs to avoid the appearance of a token survivor.
- 9. Follow program format as outlined in the Implementation Guide and document that each program contains both "witnessing" and breast and cervical cancer education components.
- 10. The training coordinator must use the LHA Evaluation form in Appendix A to ensure that LHAs present facts, resources, and teach BSE in a clear, easily understood manner.
- 11. The project director / coordinator or designated (experienced) WRM will assess the effectiveness of "story telling" by WRMs.
- 12. Witness Project® partners must:
 - use cancer education literature that is in agreement with current national guidelines;
 - use a certified BSE instructor to teach LHAs how to perform BSE;
 - offer annual continuing education to LHAs, especially those who teach BSE, and
 - provide annual continuing education to WRMs who want to sharpen their speaking skills.

Other responsibilities of partners include:

- Serve as collaborators in establishing additional standards for the Witness Project®.
- The project director/coordinator must attend National Partners' meetings or send an appropriate representative. Specific funding for these meetings **may** be covered by the CDC grant for a limited period.
- Send a representative(s) (WRM or LHA) to the Spring AMEN Revival (specific funding **may** be covered by the CDC grant).
- Provide discussion and written input for necessary revisions to the *Implementation Guide Package* based on program experiences and progress.
- Report process outcomes via the Witness Project® progress report form (April 10th, July 10th, October 10th, and December 10th), and participate in Bi-monthly conference calls.
- Report additional information as requested.
- Implement a plan for navigating women into preventive health services (mammograms, Paps, pelvic exams, clinical breast exams).
- Use the Program Registration Form to assess the service and / or information needs of program participants to assist those who have

requested assistance in obtaining breast and cervical cancer screenings and also follow-up with participants who documented they were not getting regular screenings.

- Meet with the WP R&D staff for site visits for the purpose of assessment for technical assistance and follow-up.
- Serve as collaborators in determining the effectiveness of the evaluation process for Witness Project® Programs.

The Witness Project's® responsibilities to partners and pilots: The responsibilities of *The Witness Project*® are as follows:

- *The Witness Project*® (WP) is responsible for liaison with and meeting requirements of the Centers for Disease Control and Prevention and acts on behalf of all Witness Project® teams regarding the Replication and Dissemination (R&D) of the WP.
- The staff of the WP will analyze data as submitted and supply partners with outcome and progress reports.
- The WP staff will assist with travel arrangements for meetings and the AMEN Revivals, and organize all meeting schedules, agendas, minutes and materials to support partners.
- The WP staff will update and revise the Implementation Package as needed and distribute revisions to partners.
- The WP staff will maintain the WP web-site and listserv and communicate with partners on an on-going basis.
- *The Witness Project*® may assist partners in procuring WP publicity materials (magnets, pins, bags, business cards, etc.) at cost.
- The WP staff will publish a quarterly national newsletter and seek input from partners and highlight progress, WP activities, and points of interest to all sites.
- Conduct site visits with partners for the purpose of assessment for technical assistance and follow-up.
- Collaborate with partners and pilots to determine the effectiveness of the evaluation process for Witness Project® Programs.
- Provide feedback reports as a result of site visits and any technical assistance required.
- Organize and conduct National Partners' meetings for partners. Specific funding for these meetings may be covered by the CDC grant.
- Invite partners to send a representative(s) (WRM or LHA) to the Arkansas Spring AMEN Revival. Specific funding **may** be covered by the CDC grant.

 Provide the *Implementation Guide Replication Package* and technical assistance as needed.

Point of Contact: The official point of contact for National Replication and Dissemination of the Witness Project® is that person designated as Project Director of the Witness Project®. This person directly oversees the components of the Replication, and Dissemination of the Witness Project® - Implementation and Evaluation Outcomes.

Implementation of Memorandum of Agreement: Implementation of this <i>Memorandum of Agreement</i> will be guided by <i>The Witness Project</i> ®, National Witness Project® Advisory Board, and National Witness Project® Partners. This <i>Memorandum of Agreement</i> shall become effective when signed by all parties and shall remain effective for the period By their execution
below, the parties hereto have agreed to all of the terms and conditions of this Agreement.
Witness Project® Partner
Signature
Date
By:
Title:
The Witness Project® Project Director
Signature
Date
By:
Title:

Mission Statement хi



THE WITNESS PROJECT®

MISSION STATEMENT:

The Witness Project® is a culturally competent, community-based, breast and cervical cancer education program through which cancer survivors and lay health advisors increase awareness, knowledge, screening, and early detection behaviors in the African-American population in an effort to reduce the mortality and morbidity from cancer.

> In church, people witness to save souls, At *The Witness Project®*, they witness to save lives!

STATEMENT OF NEED:

African Americans have the highest overall age-adjusted rates of cancer incidence and mortality of any United States population group. Despite a somewhat lower incidence rate, the five-year survival rate for African American women with all stages of breast cancer is notably lower than the rate for white women. And, African American women are twice as likely to develop cervical cancer and nearly three times as likely to die from it. Pap tests, pelvic exams, mammography, clinical breast exams (CBEs), and monthly breast self-examination (BSE) are proven methods for increasing the early detection of cervical and breast cancer, and decreasing death. Poor, minority, and elderly women, however, especially in rural areas, are less likely to practice cancer screening.

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Research has shown that barriers to participation in cancer screening activities for African American women, particularly in rural areas, include cost and/or lack of insurance, transportation problems, access-related factors, inconvenience and lack of time, lack of physician recommendation, psychological factors such as fear and fatalism, lack of knowledge and awareness of breast cancer, and misunderstanding of recommended screening frequency.

Surveys consistently find that African Americans are less knowledgeable than whites about most cancer-related issues. They often delay seeking health care so their cancers are frequently diagnosed at later stages. Although screening mammography rates continue to rise in the general population, minority and low-income women have increasingly lower utilization rates.

Cancer education messages must meet the needs of individuals at all literacy levels. Low-income and limited-literacy populations have not been adequately reached by cancer control strategies. Although a large number of Americans are functionally illiterate, particularly lower socioeconomic and African American populations, typical printed cancer education materials are written at the 10th or 11th grade reading level.

PRELIMINARY WORK:

The Witness Project® was initiated in 1990 by Deborah O. Erwin, Ph.D., a medical anthropologist at the Arkansas Cancer Research Center, University of Arkansas for Medical Sciences, and Thea Spatz, Ed.D., a certified health education specialist at the University of Arkansas at Little Rock.

It was developed in cooperation with the American Cancer Society (Mid-South Division), Arkansas Department of Health, Delta Health Education Center, and local churches and community groups.

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Preliminary work in 1990 was supported by a Cooperative Research Grant from the University of Arkansas at Little Rock and a one-year demonstration Project Grant from the Arkansas Division of the American Cancer Society (now referred to as the Mid-South Division).

The Witness Project® was the first program in Arkansas to focus on socioeconomically disadvantaged women through African American churches. Drs. Spatz and Erwin used anthropological fieldwork, individual interviews, and focus groups to assess the population's needs and to develop and quantify the intervention study. The intervention follows the 4MAT System which presents educational material sequentially to address four distinct learning styles and brain hemispheric preferences. Story-telling and experiential learning techniques are used in the intervention, rather than a traditional didactic presentation.

The Witness Project® creates a personal connection between the messenger and the audience in a non-threatening atmosphere. The result is a cancer education intervention that works for African American women.

In 199 1, a pilot study was funded by a Title XX Grant from the Arkansas Department of Health. Data from the pilot was published in 1992. From 1992 to 1996, research on *The Witness Project*® was supported by the Susan G. Komen Breast Cancer Foundation. In 1995, a 3-year proposal to the National Cancer Institute for an R25 Training Grant to expand the project into additional Delta counties was funded.

Concurrently, a supplemental grant from the Centers for Disease Control and Prevention (CDC), funded through the Arkansas Breast and Cervical Cancer Control Program (ABCCCP) at the Arkansas Department of Health, was awarded to support research to validate the intervention's effectiveness in increasing utilization services through local health units.

The Witness Project® received the National Honor Citation from the American Cancer Society in 1991. Locally, the program received the Wilowe Institute Achievement Award in 1993. The 1995 HOPE Award in the Outstanding Group

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Category was presented to the project by the Biennial Symposium on Minorities, the Medically Underserved & Cancer.

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In October 1996, the project received the prestigious Profiles in Progress Award from the Sponsors of the National Breast Cancer Awareness Month. One of 165 local cancer education groups across the country to be recognized during the 10th annual National Minority Cancer Awareness Week, the project received a National Cancer Institute Partnership Award in 1996 for outstanding efforts to reach minority populations with cancer information.

CURRENT ACTIVITIES:

Witness Programs: Witness Project® programs are presented in churches and community centers by Witness Role Models (WRMs) and Lay Health Advisors (LHAs). WRMs are African American women who are breast or cervical cancer survivors. Their presence as survivors is seen as a blessing and proof that cancer is not a death sentence.

LHAs are not cancer survivors themselves, but are women who want to work with the project to organize and publicize programs, network with community people, answer questions about cancer screening services and available resources, teach BSE, and encourage preventive health services (mammograms, clinical breast exams (CBEs), pelvic exams, Pap tests, and BSE).

During a Witness program session, WRMs witness by talking about their experiences with cancer, stressing the importance of early detection and answering questions about their personal experiences, fears, and concerns. Witnessing is done by 2 to 5 WRMs (at least 2 WRMs to avoid the appearance of a "token" survivor).

The educational session addresses the fears and beliefs many women hold about cancer, demonstrates that the diagnosis of cancer is neither a death sentence nor a punishment, and provides participants with accurate, personal information about cancer, early detection and treatment methods. During the session, LHAs give breast and cervical cancer facts, inform participants of available cancer screening resources in the community, and following each session teach BSE using ethnic breast models.

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Recruitment and Training Programs: Potential WRMs and LHAs are recruited at program sessions, as well as through personal contacts, exhibits and displays, and some local advertising. Specific criteria in the Implementation Guide provide a basis for selection of trainees. Training sessions are scheduled as 1-day (8-hour) programs during which LHAs and WRMs meet together for the first 2 hours, then separate into groups for specialized training. LHAs learn about available resources, breast and cervical cancer facts, early detection and how to teach BSE, while WRMs develop their narratives.

WRMs who want to serve in a dual role and teach BSE return for a second day of training to complete the LHA training curriculum.

Community Advisory Board: The Advisory Board guides training and networking in expansion counties. Community leaders and representatives from a wide variety of institutions are appointed to the board, which meets quarterly. Members help assure acceptance and assimilation of the project in their communities.

Steering Committee: The original WRMs and LHAs serve as an executive-style committee that meets monthly to achieve project objectives. This committee structure allows team members to maintain ownership of the project, as well as to contribute personal experiences and guidance for its success. Steering committee members provide valuable social, cultural, and personal networking expertise.

Research: The first phase of research for *The Witness Project*® included intervention and control groups of women from the Arkansas Delta region. Women in the intervention and control groups were interviewed at preintervention and 6-month follow-up to assess beliefs, attitudes, knowledge, and practices related to breast and cervical cancer screening. Women who participated in Witness programs demonstrated significant increases in mammography and BSE.

Baseline measures demonstrate that the intervention is reaching low-income, less educated minority women who have previously been difficult to contact through traditional health education methods. Accepted and supported by African

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American church groups and communities, it is effective in drawing low-income, less educated, rural African American women to participate.

Significant behavior changes which are influenced by participation in a Witness program have been documented. Of every 100 women who normally do not get mammograms, an average of 23.6 sought and received a mammogram in the 6month period following the intervention.

Of every 100 women who did not practice BSE, 69.4 practiced BSE regularly after the intervention period, compared to 60.7 who practiced BSE in the prior month. Of every 100 women who had not received clinical breast exams, 18.8 received one in the follow-up period.

Drs. Erwin and Spatz suggest that the intervention changes behavior because the messages are crafted to *meet* the women's beliefs, rather than to *change* the women's beliefs.

Instead of trying to dispel a belief or a myth, or overcome beliefs which center around the power of God's will versus the power of biomedicine, the WRMs present their stories within the framework which honors culture and local health beliefs. Their very presence as cancer survivors is evidence supporting God's will. Cancer education programs need to incorporate and honor concepts (like religion) within interventions.

A second phase of research, funded by the Arkansas Department of Health through the CDC, investigated short-term and long-term behavior changes related to program activities in two intervention and two control counties. In this study, a quasi-experimental pretest and posttest design was used to measure the effectiveness of The Witness Project® in increasing the practice of BSE and mammography by rural African American women in 2 counties. Program participants were compared with a control population of African American women who did not participate in the intervention.

The authors hypothesized that women who attended *The Witness Project*® programs in the intervention counties would show a significant increase in the practice of BSE and mammography compared with the controls. Women in all

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counties were exposed to national, state, and local media reports, and marketing campaigns promoting the early detection of breast cancer.

The Witness Project® was developed with a theoretical base in health educational learning styles, and ethnographic fieldwork. The concept is to have African American women who have survived breast and cervical cancer present themselves as role models to promote early detection through presentations given in churches. Both the message and the messenger incorporate spiritual and faith components that are essential to the lives of the participants. For many small, poor, rural communities, churches have been the only civic and organizational infrastructure in existence, so they offer a prime site for the intiation of health education. Results of the study were that Witness Project® participants significantly increased their practice of BSE and mammography compared with the women in the control counties.

These results demonstrate that intensive community-based, culturally competent educational programming incorporating the spiritual environment of the faith community, such as The Witness Project®, can positively influence breast cancer screening behaviors among rural, underserved African American women. Through the use of community churches and cancer survivors, breast and cervical cancer screening activities can be improved in this population.

Exhibits: A series of black and white portrait photographs was produced by local photographer/artist Andrew Kilgore with the support of the Susan G. Komen Breast Cancer Foundation and the American Cancer Society. These framed photographs and a description of *The Witness Project*® are exhibited to generate interest in the program. In addition, a portable exhibit which displays photographs and educational and recruitment messages is available for promotional activities.

Video: A 13-minute VHS video, If I Can Help Somebody: Witnessing to Save Lives, was developed in 1995 as a tool for ongoing breast and cervical cancer screening and education programs or for African American cancer support groups. Production of the video was supported by the Avon Breast Health Access Fund. In 1995, the Arkansas Chapter of the International Association of Business Communications (IABC) presented a Bronze Quill Award of Excellence to the Arkansas Witness Project® for the video, an established mark of excellence in the business communication profession.

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The video depicts African American breast and cervical cancer survivors in the church setting, telling the audiences of their experiences with cancer and why it is so important to practice early detection methods such as BSE, mammography, clinical breast exams (CBE), and Pap tests. A facilitator video, Training Survivors to Witness . . . A New Approach to Saving Lives, was released in 1996.

Implementation Guide: In response to requests from cancer centers and health organizations wanting to implement a Witness Project® in their regions, the training curriculum was published in 1996 and revised in 1998 and again in 2000. An interactive process with minimal reading and didactic requirements, this training curriculum addresses the adult education needs of lower income and less educated African American women.

The curriculum is supported by a program manual that is divided into two parts. Part I: An Implementation Guide, includes instructions for setting up and maintaining an outreach program; recruitment; evaluation; administrative guidelines; publicity methods; the theoretical basis of the program; forms; references; and an extensive resource list. Part II Facilitator Training Manual, contains the actual training curriculum instructions and guidelines, specific training agendas for Witness Role Models and Lay Health Adivsors, other forms specific to training and programs, and 80 colorful training slides all arranged in 3ring binders.

Content and technical aspects of the Guide were peer reviewed, and the Guide earned an Award of Merit for Writing, Editing, and Design from the Society for Technical Communication in the 1995 Annual Technical Publication Competition. Publication of the guide was supported by the Arkansas Chapter of the Susan G. Komen Breast Cancer Foundation and the National Cancer Institute.

Newsletter: To improve communication among the growing number of WRMs and LHAs, a brief newsletter, Reaching Out, was initiated in October 1995. Published on a quarterly basis, the newsletter introduces new WRMs and LHAs, announces special activities, offers health hints, and delivers news.

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The Witness Project® also has national partners replicating the project in 17 states across the nation. Therefore a national newsletter, Reaching Out, National Edition was initiated in March of 1998. Similar to the state newsletter, it announces special activities, meetings, offers health hints, is published quarterly, but delivers national news.

Annual Meeting for Education and Networking (AMEN Revival): An annual meeting was initiated in 1996 to meet three objective: (1) to increase cancer awareness and the number of Witness Project® volunteers; (2) to update breast and cervical cancer knowledge; and (3) to provide a forum for African American breast and cervical cancer survivors to network and support each other.

The program is planned by a committee of WRMs and LHAs. Recognition awards, including Outstanding Service (for service hours), Program Award (for program participation), and Outstanding Achievement (for programs and service hours), are announced and Annual Service commemoratives and honorariums are distributed. Held prior to National Minority Cancer Awareness Week, the meeting attracts African American women who are breast or cervical cancer survivors or who are at risk for developing these diseases, as well as those considering starting a Witness Project®.

National Replication and Dissemination of the Witness Project®: In 1997, The Witness Project® entered into a funded, cooperative agreement with the CDC to replicate and disseminate (R&D) the model in up to 12 community-based sites nationally over a 4-year period. The current sites include non-profit organizations, churches, private hospitals, and public health providers. The Witness Project® also has national affiliates -- sites that heard about our program, purchased *The* Witness Project® training materials, and signed a Trademark/License Copyright and Agreement and Memorandum of Agreement to replicate the program in their areas.

The Witness Project® has a national scope with projects in thirty-five sites encompassing twenty-two states.

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Current expansion of *The Witness Project*® is supported by the:

- Centers for Disease Control and Prevention
- National Cancer Institute

For more information on *The Witness Project*®, please call either 1-800-275-1183 or 1-800-767-3824, or visit our Witness Project® web-site at witnessproject.uams.edu

Volunteer & Professional Staff:

Without the African American women who agreed to be trained as the original Witness Role Models (WRMs), there would be no *Witness Project*®:

Ms. Dorothy Ballard Ms. Gladys Lee Hallman

Ms. Ethel Davis Ms. Ollie Jennings Ms. Lillian Dokes Ms. Ruby Lindsey Ms. Charlie Stayton Ms. Cleo Dunnings (deceased) Ms. Alice E. White Ms. Gladys Hallman

The following dedicated team members serve as the steering Committee for the project, and are faculty for the training program. True foot soldiers in the war against cancer, they are the heart and soul of *The Witness Project®*:

Ms. Ethel Davis Ms. Linda Shelby Ms. Gladys Hallman Ms. Charlie Stayton Ms. Ruby Lindsey Ms. Mattye J. Willis

Ms. Christine Oliver

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Other members of the professional staff of *The Witness* Project® who are instrumental to the success of the project are:

Charlie Stayton, Executive Director Mattye J. Willis, Deputy Director Regina Shoate-Gibson, RN, Project Director James Chastain, Evaluation Coordinator Marilynn E. Fulton, Research Project Analyst Regina Tausan, Financial Manager Patricia Drobka. Administrative Assistant

At the University of Arkansas for Medical Sciences, Suzanne Klimberg, MD, a surgical oncologist who specializes in breast cancer, provides clinical expertise to The Witness Project®.

Through their support of the Arkansas Witness Project®, the following organizations are largely responsible for its success:

- American Cancer Society, Mid-South Division
- Arkansas Cancer Research Center at the University of Arkansas for **Medical Sciences**
- Arkansas Breast and Cervical Cancer Control Program at the Arkansas **Department of Health**
- Avon Breast Health Access Fund
- Central Arkansas Radiation Therapy Institute
- Delta Health Education Center
- National Black Leadership Initiative on Cancer
- Susan G. Komen Breast Cancer Foundation
- Health Education Program at the University of Arkansas at Little Rock

History of Program Development of The Witness Project® 1990 1991 1993 1994 1995 1989 1992 Susan G. Komen NIH / NCI R25 Cancer Susan G. Komen support to Develop Pilot Study funded Susan G. Komen Education Grant \$111,614 methods. by the Title XX Breast Cancer Breast Cancer develop Breast Cancer Recruit Grant - Arkansas Foundation Grant Foundation Grant methods to Foundation Grant Department of \$37,000 \$35,500 Susan G. Komen Breast Cancer Role increase use of (National) \$25,000 Foundation Grant \$37,000 mammography Models Health (ADH) First oral Avon Grant through among rural \$20,000 University of the Cancer presentation of The \$15,000 ADH Grant African Arkansas at Little American Registry First Witness Witness Project® at \$100,000 Rock Incentive Project® program the Biennial The Witness Project® women Grant \$4,000 at Shiloh Baptist Symposium on invited to Washington, Begin recruiting WRMs and \$9,000 Minority, the D.C. to present to LHAs statewide American Church, Little Rock Role Models Cancer Society Underserved and Rural Women's (April) recruited and \$2,800 Cancer (ICC) Health briefing at the "If I Can Help Somebody, trained in West First oral abstract Witnessing to Save Lives" video University of White House. Helena (Phillips Arkansas at presentation of The Arkansas Leadership produced County), eastern Little Rock Witness Project® Award - Wilowe Andrew Kilgore Arkansas American photograph exhibit Initiated Arkansas State Institute, AR Association for produced of Witness Newsletter "Reaching Out" Pilot data Cancer Education. Role Models published, Journal HOPE Award presented by the Baltimore, MD of Cancer Biennial Symposium on Education National Honor Minorities, Medically Citation -Underserved and Cancer American Cancer Award of Merit for Writing, Society Editing and Design from Society for Technical Communication **Column A:** The number of women reached through Witness project® (video) programs each year / number of WP programs.

1

Column B: The cumulative number of women reached.

Bronze Quill Award - Arkansas

History of Program Development of The Witness Project®

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1996	1997	1998	1999	2000
NIH/NCI R25 \$111,614	Centers for Disease	CDC - R&D \$290,152	CDC – R & D \$290,152	CDC – R & D \$290,152
ADH - \$100,000	Prevention (CDC) – Replication and	Arkansas Komen Affiliate \$17,121	AR Komen Affiliate \$18,000	AR Komen Affiliate \$44,000
AR Komen Affiliate Grant \$8,500	Dissemination Grant	W17,121	Cancer Practice article published	ADH - to pilot Navigation
First Edition of Witness Project® Implementation Guide published	\$290,152 (4 year grant)	150 WRMs and LHAs trained in Arkansas	demonstrating statistically significant increase in mammogram and BSE compared to control	program for The Witness Project® \$50,000
First AMEN Revival (Annual Meeting for Education & Networking)	NIH/NCI R25 - \$111,614	Began acquiring National Witness Project® affiliates	population	Journal National Medical Association article published
Journal of Cancer Education article published data demonstrates statistically significant increase in mammograms & BSE	Avon - \$68,834 ADH - \$100,000	"Reaching Out, National Edition" Newsletter initiated		on qualitative data regarding barriers
Adult Learning article published	AR Komen Affiliate grant \$8,888	2 nd Edition of The Witness		
NCI Partnership Award for outstanding efforts to reach minority population	- '	Project® implementation Guide published		

Column A: The number of women reached through Witness project® programs each year / number of WP programs.

Column B: The cumulative number of women reached.

Profiles in Progress Award from National Breast Cancer Awareness months

Silver Mature Media Awards for "If I Can Help Somebody, Witnessing to Save

Gold Award. Health Promotion/Disease and Injury Prevention (video) from the

Annual National Health Information

Sponsors, New York, NY

Lives" video

Award

INTRODUCTION

The purpose of this section is to provide background information and define the roles of project volunteers.

After studying this chapter, you should be able to:

- 1. Explain The Witness Project® design.
- 2. Describe the intended audience.
- 3. Compare WRM and LHA roles.
- 4. List three social patterns that prevent some African American women from finding cancer early.
- 5. List 3 barriers that prevent some African American women from attending traditional health programs.

The Witness Project® is a breast and cervical cancer education program for African American women. It is designed to increase the number of African American women who practice regular cancer screening through breast self-examination (BSE), mammography, clinical breast examination (CBE), pelvic-exams, and Pap tests.

This program empowers women to take responsibility for their health needs and to overcome some of the fatalism so often found among African American women. It addresses the fears and beliefs many women hold about cancer, demonstrates that a diagnosis of cancer is neither a death sentence nor a punishment, and provides accurate, personal information about early detection and treatment.

The Witness Project® grew out of research using interviews, surveys, and focus groups with African American women in Arkansas.

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The project has a strong theoretical base in health education, learning styles, and anthropology. Its concept is simple: providing culturally appropriate role models that promote early detection.

Since our first program in 1991, we have learned the value of partnering with other organizations to strengthen the effectiveness of the project. The Centers for Disease Control and Prevention's (CDC) National Breast and Cervical Cancer Early Detection Program (NBCCEDP) works with states and other national partners to assure that eligible women receive prompt referral and followup. Many partners have supported The Witness Project® including the American Cancer Society, Susan G. Komen Breast Cancer Foundation, and Avon Breast Health Access Fund

This manual is for those of you who want to replicate a Witness Project® in your community. Whether you are state health department nurses, health educators, social workers, or lay persons, this manual is written simply so that the implementation process goes smoothly.

In the pages that follow, you'll explore *The Witness* Project® model and review, if you like, the theoretical basis of the program. We will give you our ideas about setting up and maintaining an effective outreach program, and alert you to some of the special challenges you may encounter. We will explain how to train your recruits and suggest training agendas.

And we have included suggestions for recruitment, evaluation, and publicity, as well as forms, references, and resources.

© 2000 The Witness Project® Revised 03/2004 We want to know how things are going with your project, which is why we have included specific reporting forms for you to use that are located in Appendix A. Good luck with your project!

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Background

Witness programs are presented in the African American community through local churches or other organizations.

In church, people witness to save souls. At *The Witness Project*®, they witness to save lives!

At the heart of *The Witness Project*® are African American women who talk to other women about the importance of early detection of cancer -- either as Witness Role Models (WRMs) or Lay Health Advisors (LHAs). They challenge women to take care of their health and that of their families, friends, and neighbors. They help people develop behaviors that focus on preventive health and appropriate medical care.

Witnesses or WRMs are African American women who are breast or cervical cancer survivors and who witness -or talk -- about their cancer experiences.

Although the program remains focused on breast and cervical cancer education, our WRMs include women who have survived other cancers; and who have responded to our call for survivors to "witness".

WRMs answer questions about their personal experiences, fears and concerns. Their presence as survivors is seen as a blessing and proof that cancer is not an automatic death sentence.

The Witness Project® Revised 03/2004 As cancer survivors, WRMs demonstrate:

- It's okay to talk about cancer.
- Cancer is not a punishment.
- God is still with them.
- There are ways for women to take care of themselves, such as having regular mammograms, pelvic exams, and Pap tests.
- Women have a right and a duty to take care of themselves.

Women who have survived cancer assume new spiritual and social importance from working in the project. They are able to take the lead in creating cancer education awareness within their communities because of their cancer experiences.

LHAs are women who are not cancer survivors themselves, but want to work with the project. They can organize and publicize programs, network with community people, answer questions about services, and teach breast self-examination (BSE).

WRMs and LHAs do not have to be recruited from any particular churches and should be expected to reach African American women through any church, social, or community group.

Culture and **Ethnicity**

Culture provides us with the rules, beliefs, traditions, attitudes, and norms we use to deal with the world. People define their world and structure their lives according to their cultural beliefs. Culture affects the way we dress, the foods we eat, the music we listen to, and our relationships with other people. Culture unites the shared values, traditions, customs, arts, history, folklore, and institutions of a people.

Culture is learned, and cultural knowledge is passed from generation to generation. People with common racial, geographic, or religious backgrounds maintain cultural bonds that affect their behavior, and they tend to have more in common with members of their culture than with those outside of their group.

All cultures have beliefs about illness and disease that are based on folk wisdom, tradition, and custom. Sometimes these run counter to current research and scientific information. As our environment changes, some things within our culture are no longer functional.

Ethnicity is not the same as culture. Ethnicity refers to a group of individuals who share physical traits. Their heritage may or may not be traced back to the same geographic area. Most of our Witness Project® experience is within the southern, rural African American population.

Though of similar ethnic origin, not all African Americans share the same cultural attributes.

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Some ethnic groups from the Caribbean or more recent immigrants from African nations may have very little in common with African Americans. There is, in fact, a large variation. Some experiences and cultural attributes seem to be universal; others may not be. Keep in mind that ethnic groups relate to each other. It is vital to match groups to best facilitate acceptance of teaching. For example. African Americans immigrating to this country are not accepted in the same manner as African Americans born in this country.

In addition to culture and ethnicity, social class predicts and controls behavior. The social class of an ethnic group affects income, education, access to healthcare, and the nature of patient interaction with doctors. Social class characteristics can compromise cultural factors.

It is important that you define the cultural beliefs of your audience. They may be different from yours. How do they traditionally learn? Who will they accept information from? Tradition has a great influence on learning styles of groups. You will gain respect and trust by incorporating cultural beliefs into your project.

Our research and experience with this project identified several social patterns within the African-American culture that discourages early cancer detection:

African American women are unique in their response to cancer. Many don't talk about cancer. They don't want other people to know they've had cancer. But this response is changing in some areas. The goal is to change the response in all areas. The Witness Project® is initiating a culture change – from women who don't talk about their cancer experiences, to those who do.

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- Because many African American women are diagnosed with late stage disease and are likely to die of the disease, they often believe that *cancer* = *death*.
- Many African Americans still feel cancer is some kind of unclean, unspeakable disease that people bring on themselves or that signifies some form of punishment.
- Generally, older African American women are reluctant to perform breast self-exam or expose their breasts for a mammogram.
- Lower income African American women often did not have access to prevention, screening, or health promotion through medical services.
- African American women nurture everyone but themselves. As long as other family members require their attention, they are likely to put off spending time or money on themselves.
- A concern in many African American churches is "talking things into existence." This refers to the belief that another can "speak this onto me or into my life," as if talking about cancer detection increases the chances of having the disease.

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Audience

African American women in the lowest educational and income levels do not generally attend traditional health education programs such as a health fair or a mammography van visit.

Studies consistently show that African Americans know less about cancer than Caucasians. And African American women, particularly older women, are less likely to get regular mammograms, clinical breast exams, pelvic exams, and Pap tests.

There are factors in particular that may account for this lack of participation:

- They are less likely to know about or discuss breast cancer with other women.
- Few African American women know other African American women who have routine mammograms or who have survived breast or cervical cancer.
- They may not be familiar with the screening process and may not know they can get mammograms and Pap tests free or at a reduced cost through Medicare, Medicaid, or other screening programs.
- Many of them don't trust any free services. People from poor, rural communities are often suspicious of the intent, outcome and hidden costs of health services.

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Because of suspicion, lower income, less health insurance coverage, and other social and cultural factors of African American women, physicians may be less likely to refer them for cancer screening.

- Since they often see the doctor only when they have an acute problem, there may be fewer opportunities to discuss screening and prevention.
- The health care delivery system has a responsibility to ensure that there is no discrimination in practice and that all women receive recommendations and information about cancer screening.

The Witness Project® promotes cancer screening and early detection in a manner that upholds the values of the African American woman.

Churches

Because *The Witness Project*® recognizes the importance of religion and spirituality in the lives of African American women, it is designed to work within the framework of their local churches. African American churches have a long history of dealing with health and human service needs in the community. And The Witness Project® has a history of acceptance and support by African American churches.

The Witness Project®

In rural southern communities, the church is a major institution of social control, fellowship, and education. In the Arkansas Delta, for example, between 74% and 90% of African American women 18 and older attend church regularly. Our rural Delta counties have 25 to 60 churches each, with an average congregation of 100.

Church members encourage attendance at witness programs by personally inviting members of the congregation, friends, neighbors, and relatives. Ministers, elders, and other church leaders develop a personal interest in the project and encourage women to participate. This approach reaches women who will attend a social event sponsored through the church but might not otherwise attend a health program.

Witnessing is a common activity in many Christian churches, so WRMs are comfortable with this approach. Typically, a person witnesses (or testifies) to share her personal religious experience with Jesus Christ or the Holy Spirit with the congregation. Witnessing is intended to help others in the congregation who are struggling with serious problems and encourage them to follow religious teaching.

Witness Project® sessions open and close with a prayer (hymn and scripture are optional). WRMs have a natural inclination to quote scripture and refer to each other as Sister when they are witnessing about their cancer experiences. They speak of their survival as a blessing and usually begin by thanking God for allowing them to be there and for the opportunity to speak.

The Witness Project®

You may want to include witnessing in other church related activities, such as missionary society meetings, church-based preventive health sessions, or special Mother's Day services. The pastor's wife can be an excellent influence in getting participation from the congregation.

In urban churches, you may find other health or social concerns competing for attention.

Many churches are active in responding to social issues such as HIV-AIDS, drug abuse, and youth violence. Ways in which *The Witness Project*® supports the church's mission will be important.

Widening The Witnessing

Building on "where two or more are gathered in my name..." some Witness Projects® have extended witnessing to include....

- beauty schools and salons
- neighborhood centers
- public housing authorities
- schools and job training centers, including the faculty
- state agencies, such as the Department of Human Services and cooperative extension services

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- businesses and factories
- county fairs
- health fairs
- sorority and fraternity meetings
- civic club meetings
- prisons
- teen groups
- church choirs

Program Goals

Although each community's Witness Project® is unique all share 2 common goals.

- The immediate goal is to increase the number of African American women in breast and cervical cancer screening programs.
- The long-term goal is to reduce death and sickness from breast and cervical cancer by increasing the number of women who use BSE, CBE, mammograms, pelvic exams, and Pap tests to find cancer early.

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By organizing a Witness Project®, you help spread the good news about finding cancer early. Your efforts will have a positive impact on the awareness, knowledge, and screening of African American women in your community. Ultimately, this is the only way we have to lower the death rate and suffering from cancer.

Three strategies will enable your project to meet the two common program goals.

- 1. WRMs and LHAs are recruited from churches. community groups, or work sites as the opportunity presents. WRMs, LHAs, and staff assist in the recruitment process.
- 2. LHAs are trained to organize outreach programs that promote early detection of breast and cervical cancer.
- 3. LHAs and WRMs present programs locally to maximize attendance whenever the opportunity arises.

As a grassroots outreach effort, your Witness Project® will respond to your community's specific needs. This Implementation Guide will take you through the different steps. It will get you started and give you ideas for keeping your unique project going. We wish you much success!

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15 **Project Partners**

PROJECT PARTNERS

This section suggests the basic partnerships you are going to need over the life of your project. This information will help you determine who you should partner with to help make your program a success.

After reading this section, you should be able to:

- Describe the composition and responsibilities of a Community Advisory Board.
- Give examples of organizations that may affiliate with 2. your Witness Project®.
- Describe the financial resources you will need to 3. implement your project.
- Describe the in-kind services you may be able to use.

Although *The* Witness *Project*® model is simple, it takes a lot of time and energy to get an outreach project going and keep it on track, especially in the beginning. After all, you are selling a product -- cancer education -- that most people do not want.

The success and effectiveness of your project will depend largely upon establishing relationships with partners who will buy The Witness Project® concept and help sell it to the community. We are reporting what worked well for us. The needs of your community and the goals of your sponsoring organizations will determine the specific roles and tasks of each partner in your project.

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Community Advisory Board

Begin your Witness Project® by forming a Community Advisory Board. This group will advocate for the project with community members and organizations and provide personal networking expertise.

Invite community leaders and representatives of local health related organizations to guide the development of your project. If your project covers large regional or statewide areas, be sure to represent all geographic areas.

Although this can create time and travel burdens, you can limit the number and length of meetings.

A well-rounded board may include representatives of...

- local cancer programs, like the American Cancer Society and Susan G. Komen Breast Cancer Foundation
- public health professionals, including your state director of the Breast and Cervical Cancer Control Program
- healthcare and social services
- professionals including the Black Nurses Association, the Visiting Nurses Association, and others directly involved with breast cancer such as physicians, surgeons, radiology technicians and, counselors
- ministers
- African American business owners

- local media
- beauty supply owners or representatives
- local citizens
- several cancer survivors

When you approach prospective board members, be prepared to explain what you expect of them and how often you plan to meet. Let board members know that you will need their assistance in ...

- providing guidance and community-based knowledge
- suggesting effective and creative ways to reach the audience
- opening the doors to community organizations and churches
- identifying potential WRMs and LHAs
- establishing media contacts for publicity
- providing local support and credibility for the project

The Community Advisory Board will be most active when you are starting your project.

We recommend the board meet monthly for at least 3 times, then quarterly. It's also a good idea to get a consensus about meeting times and places.

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Clarify up-front any potential conflicts of core beliefs between The Witness Project®, members of the project's Community Advisory Board, and partners. For example, Planned Parenthood as a Witness Project's sponsoring organization in a strong Roman Catholic community may be problematic. Be sensitive to politics within the faith community itself. Contact the church's pastor before scheduling a program to address any concerns he or she may have.

If there is access to video conferencing in several sites, it may be a good alternative to travel for some members. Many universities, rural health care agencies, educational facilities and some commercial businesses have this equipment and capability.

Affiliations

As your project grows, WRMs and LHAs will become aware of the need for medical care and assistance within the community. Your witness program project workers can promote healthcare services that are available through your institution and affiliated organizations.

The referral process, such as in screening programs sponsored by state health departments or local institutions such as hospitals, will need to be defined and structured in consultation with the institution or affiliated organization, especially since you will be helping to navigate women to these services.

By affiliating with a sponsoring healthcare agency and the local Breast and Cervical Cancer Control Program (BCCCP), your project will have access to healthcare resources and medical expertise when needed. The CDC funds the National Breast and Cervical Cancer Early Detection Programs (NBCCEDP) in all fifty states, the District of Columbia, and 15 American Indian / Alaskan Native organizations and 5 territories.

The NBCCEDP provides leadership in bringing critical breast and cervical cancer screening services to underserved women, including older women, low-income, uninsured or underinsured, and women of racial and ethnic minority groups.

Determine what your state's qualifying guidelines are and the steps necessary for women in your area to benefit from these programs. You will also want to find out which facilities or institutions accept referrals in the event of abnormal findings after screening.

Other organizations to consider partnering with are telephone companies, financial institutions, factories, and historically black universities. There may be other organizations out there; you just need to search for them as time permits. These organizations may be able to provide valuable links with the population you want to reach.

Telephone companies and financial institutions have the capability of reaching many targeted women with breast and cervical cancer screening messages through inserts in phone bills or bank statements. As for factories, you may be able to reach a large percentage of working African American women age 50 and older.

Many factories offer health and wellness in-services so it is possible that you may be able to conduct some witness programs in this setting.

The Witness Project®

Financial Resources Needed

Unless you are financially independent, you will need some funding sources. A funding source, either a sponsoring institution or a grant agency, is a VIPP (very important project partner).

You are probably familiar with local foundations that might fund your project. Also consider your local hospital or cancer center auxiliary, American Cancer Society division, local affiliate or national office of the Susan G. Komen Breast Cancer Foundation, and the Avon Breast Health Access Fund.

You can start a Witness Project® on a **shoestring budget.** We know you can because we have done it!

The scope of your project will determine the level of funding you need. Because program size and stages of development may vary, we have included sample budgets (see Appendix D, p. 9) representative of smaller, local programs as well as larger programs with regional or statewide coverage.

In deciding upon the scope of your program, look at the population you want to reach. Is your target population confined to a small area or scattered over a wide area?

Densely populated areas may require fewer WRMs and LHAs because you may be able to reach many women at a given program in densely populated areas.

You may need additional funding for speaker fees, supplies, travel, and refreshments.

Many women who will be your strongest speakers and most influential role models may not have the financial means to spend several days each month traveling and presenting programs. Even a small amount of money is an incentive that can help these women justify spending their time and energy on the project. You can pay stipends or honoraria per program, per hour, or by some other method. You may even consider department store debit cards or awards luncheons in recognition of their program efforts.

Keep in mind that an incentive like paying a stipend is a way to keep your volunteers motivated and committed to the program. Stipends may help women who are committed but not motivated to do programs because of a lack of funds, for example, to buy their lunches, get their hair done, purchase stockings, or put gas in their cars. Many of the women you are trying to reach may be on fixed incomes and their budgets will not allow these little extras but stipends will. A strength of The Witness Project® is that the women work from the heart, but you may want to use your money to reimburse costs that would be a hardship or barrier to participation.

Travel can be provided in-kind, through, for example, institution transportation, or by car-pooling. Consider reimbursing drivers for mileage when they use their cars. If you are working in a rural area, out-of-town trips can be enjoyable social times together.

You may need to beg, borrow or purchase some startup supplies. Some supplies are absolutely essential. Still, others are nice to have.

Some nice-to-have items are:

- Witness Project® pins and magnets
- Witness Project® business cards
- Witness project canvas bags

Some supplies you will definitely need are:

- Extension cord and adapter
- Portable television and VHS video player
- Breast models
- Breast cancer education literature
- Cervical cancer education literature

You may obtain cancer education literature from your local American Cancer Society office, the Cancer Information Service (a division of the National Cancer Institute), or the Susan G. Komen Breast Cancer Foundation.

We strongly recommend offering light refreshments at programs as a thank you to the sponsoring church or community group and to the participants. Meals and refreshments are also important additions to team meetings, training sessions, and board meetings.

In-kind **Services**

In-kind items are tangible resources that are contributed to your program and considered a match in cash value. Donations and in-kind services, especially for one time expenses like food and printing, can stretch a small budget.

Some corporations have employee volunteer programs that are matched with cash contributions. Others may donate products vou could use as incentives or door prizes, or used equipment such as computers and copiers, which you will most certainly need for your program.

Check with the large corporations in your area and your local United Way Volunteer Center to determine what is available.

When you are ready to seek funding, prioritize your needs for:

- supplies and educational materials,
- staffing,
- incentives, gifts, or stipends for volunteer support.

Many funding sources will require that you match a donation with cash or in-kind support. Don't overlook the value of your WRMs and LHAs' time that can be figured as a cash value of \$13.24 per hour. This rate is a national figure that is updated each year. The rate is determined by the Independent Sector Gallup Poll, for the President's Report on Labor.

If you determine that your potential funding source will accept volunteer time as in-kind match, you must maintain documentation of name, event or activity, date, and volunteer hours. The in-kind match document must be signed by the volunteer donating the time. Contact your state office on volunteerism for more information.

The Witness Projects® © 2000 Building Your Team 24

BUILDING Your Team

The purpose of this section is to give you the tools necessary to build your Witness Project team. After studying this chapter, you should be able to:

- 1. Define the responsibilities of the Project Director/Coordinator.
- 2. Describe the qualifications and responsibilities of the Training Coordinator.
- 3. Describe the qualifications and expectations of Witness Role Models (WRMs) and Lay Health Advisors (LHAs).
- 4. List a variety of methods for recruiting team members.

Project Director

Your Witness Project® program needs a leader, a Project Director, who will be responsible for the development and maintenance of the project. Since you're reading this manual, we assume you're it.

If the sponsoring organization is a hospital or state health department, there is usually a staff member who can assume the role of Project Director or you may be able to get a director's time donated from a larger organization or business.

As your project grows, you will need a full-time director. For small programs, with small budgets, the Project Director generally finishes the developmental tasks before partnerships and community cooperation is in place.

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Developmental Tasks

As the Project Director, you may have to tackle many tasks before your program is up and running. Some identified tasks are...

- Organizing meetings
- Developing partnerships
- Coordinating planning, financial, and program activities
- Building the team
- Training the team
- Evaluating the project

Don't despair -- you may not have to actually do all these things.

But, you will need to establish a mechanism for getting the jobs done.

If you are building a large regional or statewide Witness Project®, or adding the project to a more extensive outreach program, we recommend you hire one or more assistant directors or area outreach coordinators to help with day-to-day activities.

Program Trainers

Often the Project Director will be the person training project volunteers, especially in the beginning of a project. For the initial training sessions, we recommend recruiting one or more primary instructors, including a breast self-exam (BSE) certified health educator, nurse or experienced LHA or WRM (one of these should be the Training Coordinator). Your local division of the American Cancer Society may have a list of certified BSE health educators and nurses, As you gain volunteers, you should be able to train some as LHAs. The staff of the Arkansas Witness Project® Replication and Dissemination Team is available to provide training and other technical assistance to national partners and pilots. Limited training assistance or other technical assistance may be provided to national affiliates.

The Training Coordinator (BSE certified health educator, nurse, or experienced WRM or LHA) instructs potential LHAs the correct method for performing BSE. The Training Coordinator also teaches potential WRMs and LHAs the basic facts about breast and cervical cancer, the importance of early detection, and creative methods for community-based outreach, and education.

This individual also has the task of coaching new WRMs until they are comfortable and effective in telling their stories.

One of the most important qualifications of a good program trainer is experience in adult education or knowledge of adult learning principles.

Your most effective trainers will relate well to the new recruits, build trust, establish a comfortable learning environment, and have a good knowledge of community-based health education and breast and cervical cancer control issues. The ability to create a safe, experiential learning environment is crucial.

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Training sessions are best held on weekends and / or evenings, so flexibility is important. If you plan to offer several sessions during a year, you will probably want to develop a team of instructors in order to accommodate the trainers' schedules to avoid *burnout* of your trainers.

The dedication of your project workers is important for getting your project established. But your long-term success will depend on the skills and personal traits of your WRMs and LHAs who carry the message.

For your Witness Project® team and for conducting programs, we recommend...

- A ratio of 3 WRMs to 2 LHAs.
- At least 5 WRMs and/or LHAs for areas with a population less than 20,000. In larger communities you may need to train more women which will increase your pool of WRMs and LHAs, and decrease the likelihood of losing team members.
- At least 2 WRMs (to avoid the appearance of a *token* survivor) and no more than 5 witnesses at each program session.
- When you get to a program, you can decide who speaks. Not all may be able to witness, but they can serve as support for the others.

If you have several women who want to witness at a given program, you may have to set limits on the time they "witness" or tell their stories.

In Arkansas, we started *The Witness Project*® with WRMs only. A WRM may be cross-trained as a LHA, either initially or after she gains some experience and is more comfortable with the project.

You may do this, too, if you have several WRMs who are willing to cross-train as LHAs so that they are able to organize programs and teach BSE. Not all WRMs will want to become LHAs. It would be a mistake to insist they perform both roles.

We added the LHA component so that other interested women, who are not breast or cervical cancer survivors, can be involved in the project and build teams in communities without enough active survivors.

An added benefit of *The Witness Project*® model is group support. If one WRM is shy and hesitant to speak out, then 3 or 4 others coach and encourage her.

If someone is not feeling well, the others *scoop her up* and boost her spirits. Witness Projects® in Arkansas and other sites have been so effective that there has been an outgrowth of several support groups.

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Witness Role **Models**

Witness Role Models (WRMs) are African American women from all socioeconomic levels who have survived breast or cervical cancer and are willing to share that experience with others. The primary role for the WRM is to witness, or tell her story, in her own words, and offer messages of empowerment, optimism, and success as a result of early diagnosis.

Working in her community the WRM will...

- stand before a group of women and witness (talk about her cancer experience)
- attend 1 or 2 programs each month
- serve as a local cancer resource and support person
- complete monthly activity reports

Over time, the WRM will naturally become a local cancer resource and support person. WRMs can be members of any local church or just members of your community.

They need to be willing to speak to any community group or church, not just their own congregation or group.

After women attend a witness program, they may need someone to call and talk to if they have a fear or question about cancer, or if they have been told they have an abnormal mammogram.

Because they share the same culture, these women are comfortable in talking with the WRMs and trust their advice.

Most of the WRMs in Arkansas answer several phone calls each month from women who just need someone to talk to about their cancer fear or experience. Other calls come from women who have specific questions or want to discuss information one-on-one.

There may be some hesitation on the part of a WRM to respond to these calls, because they are not trained social workers or counselors.

Fears and concerns can be addressed during training sessions. The confidence to respond in a helpful and positive manner can be easily developed.

There is virtually no way, however, to stop the calls. The phone calls are a natural outgrowth of having seen a WRM take on a leadership role.

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Lay Health Advisors

The primary role of the Lay Health Advisor (LHA) is to organize programs and provide information on breast and cervical cancer for the community.

The LHA will also be a community resource for information about mammography and Pap test providers, transportation, financial assistance, and appropriate cancer education materials.

Like WRMs, LHAs can be members of any community group or church and must be willing to speak to any women's group or church, not just their own.

Working in her community, the LHA will...

- organize and lead 1 or 2 witness programs monthly
- contact ministers and community groups and organizations with information about the project
- post flyers and notices about upcoming programs
- telephone women and invite them to attend programs
- teach community residents about cancer screening practices such as BSE, CBE, mammograms, pelvic exams and Pap tests
- complete monthly activity reports

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Recommended **Qualifications**

To help you choose women, who are most suitable for your Witness Project®, we have compiled a list of the qualifications we think are important.

These guidelines will help you select WRMs and LHAs who can effectively handle their roles and responsibilities and thereby be strong team members.

We recommend you recruit potential WFMs and LHAs considering the following...

- live in the community
- share the community's language, culture, and socio-economic background
- have strong interpersonal communication skills
- are willing to work flexible hours, including evenings and weekends
- are ambulatory, with no health concerns which prevent local travel
- have a home telephone or are accessible by telephone
- are able to attend meetings (transportation is discussed in the Special Issues chapter of the manual)
- be at least 21 years old (older women are preferred)
- be able to read and write
- have good problem-solving skills

- be familiar with the community's needs, organizations, and leaders
- be able to work in a self-directed, unstructured field setting
- be committed to the community's welfare
- be willing to organize, attend, and present cancer education programs

In addition, *ideally*, a **WRM** should...

- 1). be disease free for at least 1 year after breast cancer diagnosed at Stage I or II, or cervical cancer in situ diagnosed at stage I and / or,
- 2). report a favorable outcome experience with her cancer diagnosis and treatment

However, when selecting WRMs, look at each woman individually. Not all of our WRMs were in remission while they were "witnessing." A WRM with recurrent or stage I breast cancer, should be evaluated on her ability to deliver her story in a positive manner.

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Recruitment

You can use a variety of methods to find appropriate candidates:

Cancer survivors (Witness Role Models) and Lay Health Advisors can be recruited through personal contacts.

- Word-of-mouth publicity is most effective.
- If you have physician and or human subjects research approval, you may be able to use a hospital cancer registry (the registrar can contact survivors and invite them to an orientation meeting or individual meeting with you).
- Post flyers in churches.
- Generate newspaper articles about the project.
- Television interviews are a good medium for recruiting.
- If you participate in "Race for the Cure" and "Relay for Life", try to use that time and occasion to actively recruit.

Whatever you do, start early. Initial recruitment may easily take up to 6 months.

Rely on input from the community. Included in this Implementation Guide and training literature are a video entitled "If I Can Help Somebody: Witnessing to Save Lives", and brochures that explain what *The Witness Project*® is all about.

These educational tools were developed in 1991 for use in our breast and cervical cancer education. They depict our WRMs explaining from a personal perspective why breast and cervical cancer screening is so important.

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> Use the video and brochures to approach church and community leaders. Urge them to contact qualified women they know and ask them to apply or at least be interviewed for your project.

Pastors will most likely suggest women from their congregations who are strong community health workers and / or are known to be cancer survivors. Don't overlook "informal" leaders -- those known to be gatekeepers and who are well recognized in the community as sources of information on potential recruits.

With your advisory board, make personal contacts with local physicians and nurses, community health centers, public health professionals, and local community groups such as the American Association for Retired Persons (AARP) and Cooperative Extension Service in seeking recruits. If you work for a healthcare facility, ask your doctors, nurses, mammography technicians, and cancer registrars to contact likely candidates.

Prospective witness role models, especially in the beginning, need to know they will be working with women who have had similar experiences. Your initial contacts and discussions with prospective women are very sensitive and require honesty to build trust. Usually, once a few women support the idea of the project, they will recruit others. Cancer survivors are the best and most credible recruiters.

As in any organization, some women will lose interest and drop out. You may find it helpful to select and train more women than you think you need so you'll have some alternates.

Remember that cancer is still a fearful, stigmatized disease in the African American culture and people don't discuss it.

Because of the secretiveness of the diagnosis and attitudes surrounding cancer, confidentiality is of the utmost importance.

This secretiveness also means it may be quite a challenge to locate prospective candidates who have the right balance of technical and interpersonal skills.

You probably won't have large numbers of applicants from each county or community. Don't be discouraged. You're looking for quality, not quantity.

Selection

Try to select recruits who are culturally similar to the audience you want to reach.

As women express interest in working with the project, have them complete and sign an application form. Sample application forms for WRMs and LHAs are located in Appendix A (pp. 11 & 12). After they complete an application, follow-up and visit with them either in person or by telephone. Confirm that candidates qualify. Tell them what to expect and what will be expected of them and be sure they understand. If stipends are available or expenses will be reimbursed, explain these procedures.

Schedule interviews with the applicants. In the interview, you want to learn more about the woman and her cancer experience and judge her interest, energy, motivation and commitment. Assess her sensitivity to others, ability to handle responsibility, commitment to the community, and willingness to teach and help others.

Training

Now that you've recruited your team, its time to train them. The training curriculum, agendas and instructions for training your team can be found in Part II: Facilitator Training Manual.

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MAINTAINING YOUR OUTREACH PROJECT

The success and longevity of your Witness Project® will depend on two things: community support for the project and retention of effective team members. Careful monitoring of your project is necessary to recognize its successes, problems, and the ultimate desired outcome --- that more women begin cancer detection practices as a result of *The Witness Project*®.

This chapter explains the standards necessary to maintain your outreach project. It gives you information on how to monitor your personnel, program process, and impact measures. Helpful tips are included on how to keep your team members and common reasons are given as to why team members lose interest. After studying this chapter, you should be able to:

- 1. State the program standards necessary for your success.
- 2. Critically evaluate your team members and your program.
- 3. Describe requirements for reporting to the National Witness Project® Replication and Dissemination team.
- 4. Describe the composition and responsibilities of a steering committee.
- 5. State a plan for communicating with your team members.
- 6. Develop a budget for your project.
- 7. List ideas for keeping your team active.

Standards

The Witness Project® was developed by applying proven theoretical models of health education and learning styles into a culturally specific context. Our research, supported by the growing interest in implementing the program, indicates that the concept is effective.

You are encouraged to adapt *The Witness Project*® to your community's needs and resources. Having defined standards will help your project develop and maintain a professional structure. Some standards that you will find necessary to monitor your success are...

- Annual CBEs, mammograms, pelvic exams and Pap tests and monthly BSE must be encouraged in every program.
- Both WRMs and LHAs must undergo training regardless of the experiences they bring with them.
- A program must contain both witnessing and cancer education components.
- WRMs should witness in a group of at least two but no more than five.
- WRMs and LHAs must agree to conduct at least 7 programs per year.
- Evaluation of both process and outcome is not optional; it is essential.

For a comprehensive list of standards, review the sample memorandum of agreement Witness Project® sites must sign before implementing a WP.

In evaluating process, you will be assessing the effectiveness of your team members in delivering your messages to your audiences. In assessing outcome, which may take some time, you will be able to determine if your processes were effective by changes in behavior. How many women who attended your programs scheduled mammograms and Pap tests afterwards? How many actually followed through with these tests?

You must have a defined process for referral and follow-up of abnormal mammograms and Pap tests.

Witness Project® replication sites must agree to conduct at least 7 programs each year. How often you conduct programs depends on your area and the needs of your community. There will be peaks and valleys in your schedule so don't become discouraged. The dedication and commitment of your WRMs and LHAs, the difference in abilities, and the stage of your program organization will all be determinants of how many programs you are able to conduct. If necessary, you may offer incentives to motivate your team members to schedule more programs, such as a certificate for a free trip to the beauty shop.

The next two sections of this chapter, Monitoring Your Personnel, and Monitoring the Process, should help you assess how well you are delivering The Witness Project® model.

Another section, "Monitoring Your Outcomes", describes ways to evaluate your program's effectiveness.

Monitoring Your Personnel

Evaluation of your team members actually begins at recruitment with the applications. Use the application forms for both WRMs and LHAs as a screening tool (see Appendix A., pp. 11 & 12). We recommend that a committee review applications. The committee may consist of the Project Director, Training Coordinator, and experienced WRMs and / or LHAs, depending on the size of your program.

As you interview the applicants, pay attention to hesitations, questions or instincts the committee may have. A "loose cannon" with her own agenda may not only exhaust precious time and resources, but may also destroy the credibility of your project. Never ignore a potentially good team member. A woman may feel she cannot speak in front of a group, but can help with logistics such as transportation and organizing materials. Later, she may become comfortable with public speaking.

It is important to evaluate the training your WRMs and LHAs receive to verify that they grasp and are able to apply the essence of their training. Methods will differ from one project to the next, but may include traditional tests, role-playing, observation, or focus groups.

Trainees should be given the opportunity to evaluate the training sessions, materials, and trainers.

Training evaluations should be anonymous so the trainees are secure their confidentiality is protected.

You may ask them to give written feedback after the training session or ask someone other than the trainer(s) to conduct a telephone interview a week or so after the training. It is important to identify qualitative measures of success (i.e., attendance and length of training) with regard to the training session.

We advocate using a **pretest/posttest** to assess the effectiveness of LHA training (see Appendix A, p. 15). Remember the trainees must not feel threatened by the test. Explain that it is the trainer's duty to help them understand, and that you're checking to be sure the trainer correctly taught them the material.

An apprentice period will give LHAs opportunities to hear the presentations of others and ask questions. The standard for apprenticeship is attendance/observance at 3 Witness Project® programs (or at least 3 practice/mock programs for new sites). The LHA must, at a minimum, give 3 presentations per year after having observed 3 programs.

To maintain the integrity of the project, the Training Coordinator has the responsibility for evaluating the performance of the LHA in the field. After each presentation, the observer (Training Coordinator when possible or an Area Coordinator) will evaluate the LHAs' presentation and then have her perform a self-evaluation using the same evaluation tool. They should compare and discuss the evaluations.

If the evaluation indicates areas for needed improvement, it is the Training Coordinator's responsibility to develop an improvement plan.

A sample LHA evaluation assessment form can be found in Appendix A, p. 17.

Even when a LHA is "on her own", she will benefit from feedback. Take five minutes at the end of each program to ask the LHA how she felt about her performance. Give her specific feedback concerning how well she...

- organized her presentation
- connected with the audience
- provided accurate information

All LHAs should receive **continuing education** on an annual basis, especially those who teach BSE. This training curriculum mirrors the initial training session. (See training curriculum in Appendix E).

The purpose of this training is to support the LHA as she maintains the high standards of the program. It is not intended to be punitive in any manner. Continuing education for your LHAs is crucial because research and policies in cancer detection are changing rapidly. You should build in time, either as part of another event, such as a retreat, or have a separate refresher course to update your team members with information. This is also an excellent time to recognize LHAs who have fulfilled their commitment to service and continuing education.

Evaluating the performance of WRMs is more difficult.

The idea of applying criteria to a testimonial sounds

counter productive, but it will be important to do so for your WRMs to grow as public speakers and "owners" of the program. An apprentice period and a self-evaluation process are recommended, but a formal evaluation is not necessary (see WRM evaluation form, Appendix A., p. 17). Focus on message delivery, not the content (who, what, when, where and why).

Feedback should address her ability to...

- tell a clear, sequential and purposeful story
- relate the personal aspects of her experience
- use accurate information

Communicate your feedback in a positive manner. This can be a sensitive issue -- you don't want WRMs or LHAs to feel that they are being judged or graded. Be encouraging and non-judgmental. For example, after a WRM tells her story, you might say --- I really liked your story on needing to be assertive with your doctor, but don't think you need to go into detail about your treatment. You really bring a lot of energy into the story when you leave that out.

Annual continuing education sessions must be offered to WRMs. Those who want to sharpen their speaking skills or feel more comfortable with public speaking can also take advantage of this opportunity to network and fellowship with one another. Use this opportunity to demonstrate your commitment to personal styles and the quality of the message.

Any serious problems regarding a presentation should be handled individually and confidentially.

Monitoring Your Process

Assessment of the witness program activities is a form of process evaluation (measuring your project's efforts) as you go along. This will give you valuable information about what is working and what you want to adjust for a stronger program.

At a minimum, you should record...

- number of WRMs trained
- number of LHAs trained
- WRM satisfaction (observational or self-reported)
- LHA satisfaction (observational or self-reported)
- number of programs presented, including sites held and length
- number of participants at each program and those over age 50
- participant satisfaction (observational or self-reported)
- number of WRMs and LHAs who present at each program
- comments you heard from participants after a program
- communities / towns / counties served
- contacts reported by the team members or staff for publicity and recruitment
- project partnerships and what they are contributing
- technical assistance needs and requests
- recruits who do not finish training and/or trainees who are no longer participating in the program
- number seasoned WRMs who become inactive
- number of seasoned LHAs who become inactive

Inactive, seasoned WRMs, and LHAs are those who have

not participated in Witness Project® programs within 18 consecutive months. In looking at inactive statistics, especially of seasoned WRMs and LHAs, attempt to explore reasons for their inactive status.

When you document your activities, make sure you distinguish between training sessions and community programs.

We strongly recommend you keep a log of...

- observations from someone other than the speakers
- comments and suggestions from participants, whether in person or by telephone
- publicity activities, including flyers, church bulletins and newspaper articles
- community contacts regarding the program

We also recommend that you ask your team members to submit brief monthly activity reports. These are especially useful for documenting individual time spent and the number of contacts made. (A sample activity report is included in Appendix A, p.8) It helps if you provide the WRMs and LHAs with an addressed, prepostage-paid manila envelope.

We **do not** recommend that you use a satisfaction survey at the end of a community program to assess effectiveness. To do so lessens the personal connections upon which *The Witness Project*® is built.

Instead, document how well the program was received by **observation** and **interview.**

There are several ways this can be accomplished. The Project Director or an advisory board member can attend some of the programs in the community to observe the quality of each presentation and its effectiveness in reaching the audience.

You may collect names, addresses, and telephone numbers of participants and then perform a limited number of randomly selected telephone surveys to ask them what they thought about the program.

You can ask factual questions about what they learned from the program, as well as their attitudes and beliefs about the information.

The Area Outreach Coordinator can also work questions into the conversation when she is visiting with participants over refreshments.

In what ever manner you choose to interview participants, you will want to get information beyond whether or not they liked the program.

Reporting

The Project Coordinator/Director is responsible for providing a progress report every other month and forwarding the program registration forms, informed consent forms, and follow up sheets according to instructions in Appendix A, page 23.

All reports should be mailed to the Witness Project® Evaluation Coordinator. Information from the monthly activity reports of local coordinators will give you a comprehensive view of your program's progress. A sample Progress Report Form can be found in Appendix A, p. 7.

Monitoring Your Impact

The effectiveness of your Witness Project® will be shown by **impact measures** (changes in behaviors as a result of your program). We require that you...

- Explain to participants your need to see if the program really makes a difference in cancer detection practices.
- Know the breast and cervical cancer resources available in your community, and keep in mind that some hospitals require a doctor's referral for screening mammograms, so it is helpful to know their policies.
- Explain the necessity for written **Informed Consent** upon registration (see Appendix A, p. A-3). Written consent allows you to follow-up with program participants.
- Call participants who completed a **Program Registration Form** that are not getting regular breast and cervical cancer screenings and those who have requested navigational assistance in obtaining these services within one week after a program. Once appointments have been scheduled, contact these participants again within one month of the scheduled appointment to determine if services were received.
- It may be helpful for you to establish some sort of navigational tracking tool or reminder system to ensure that calls are made.

It is important that you use experienced telephone interviewers to conduct your follow-up surveys. Try calling a local university to see if specific students are available for this. You may want to train one of your team members to conduct the surveys as we have done.

Expect some difficulty in contacting women for followup. Many participants don't have telephones and those who do may have caller ID. People may move away or into blended homes. Obtaining the participant's telephone number and / or some other number (e.g., relative, friend or work) where they can be reached at registration can improve your ability to stay in contact. Be cautious in trying to locate a program participant through other contacts. You may, with the best intentions, violate someone's confidentiality.

Steering Committee

As your Witness Project® grows, you will need a Steering Committee to manage the project. Committee members should be WRMs and LHAs elected by the group or selected in other ways. It is very important that this committee be established at the very outset of your project! The Steering Committee reflects the commitment to involvement in the project and provides a safe forum for review of the program. It is the voice of the survivors and other team members – they are in essence, *The* Witness Project®. In addition to managing the project, the Steering Committee:

- Gives feedback to the Project Director for process evaluation
- Notes new and expanding needs of *The Witness Project*®
- Identifies any problems or issues as they develop and seek to resolve them
- Ensures that the project adheres to its mission statement
- Participates in the development, implementation, and expansion of the project.
- Makes major decisions that are in the best interest of the project.

The Steering Committee is a natural forum for project planning and evaluating publicity, videotapes, brochures, and breast and cervical cancer education materials that concern The Witness Project®.

Meetings and **Communication**

Good communication between witness staff and team members is essential for your project's continued success. This can be especially challenging when staff and team members are located in different geographic regions. To keep communication lines open, publish a **newsletter** or make regular telephone calls to just touch base. Encourage team members to set up a telephone network to pass messages. Establish a routine meeting schedule.

Regular communication with community-based organizations is also important. As programs are scheduled, provide written confirmation or telephone follow-up with the organizations and churches.

We have found thank-you-for-having-us notes are especially appreciated.

We find it helpful and rewarding to have one or two social functions during the year to foster team spirit and maintain cohesiveness. These are usually held after a witness program or when the group is together for other reasons. Cancer issues are very serious, and most of the women face many difficulties in their daily lives.

We believe it is important for WRMs and LHAs to feel good about themselves, value the time they spend on the project, and to have fun, too.

We recommend you plan at least one all-inclusive annual function for your trainers, team members, advisory board members, affiliates, and sponsoring organizational staff. This event will provide social cohesiveness along with continuing education.

You can also use this opportunity to enhance pride in the project by recognizing group and individual accomplishments.

Budgets

While you may have to start a project as we did, on a shoestring budget, once the project gets up and running, you will be asking. "How much does it take?"

That is a difficult question, and your answer depends on...

- salaries and benefits of paid staff
- direct program costs, such as materials, travel, telephone, space rental, computers and printing
- sub-contracts, such as for surveys and evaluation
- stipends and recognition awards
- indirect (overhead) costs which can not be prorated (allowable rate is often determined by the funding organization and may range from 8 - 15%)
- in-kind donations
- fund-raising

As you read in Chapter 2, we have included sample budgets as guidelines for determining how much it takes to get your program going. These can be found in Appendix D beginning on page 9. The samples represent programs of varying scopes. Our advice is that you assure the quality and standards of the project when budgeting. Try using the **Expenditure Report** (Appendix A page 7) to assist you as you develop an operating budget. It can also be used as a guide in developing funding proposal.

Keeping Your Team

Keeping women active in your project will often depend upon the degree of supervision and support provided to the team members in the field and at the sponsoring organization.

Holding onto trainees through the training process and

into the project activities is sometimes very difficult.

Common obstacles include family obligations, previous commitments, and lack of funds if stipends or salaries are not available. Many community health outreach worker programs report significant dropout rates.

Of a total of 60 WRMs trained in Arkansas since 1992, 48 or 80% are active. As for LHAs, 53 have been trained in Arkansas since 1992 and 34 or 56% are active.

Team members **remain committed** when...

- their work is appreciated
- they can see that their presence makes a difference
- there is opportunity for advancement
- there is opportunity for personal growth
- they receive private and public recognition
- they feel competent doing the work
- there is a sense of belonging and teamwork
- they are involved in the administrative process --problem-solving, decision-making, and goal-setting
- something significant is happening because the group exists

Here are some common reasons why team members **lose** interest...

- expectations are different than the reality of the project
- don't feel they're making a difference
- no praise or reward
- too routine, no variety
- no support from team members

- little prestige related to the task or group
- no opportunity for personal growth
- not able to demonstrate initiative or creativity
- tension among team members
- little or no community support

A strong sense of teamwork and commitment to service encourage project workers to stay active. In our experience, the team members become a natural support system for one another and look forward for opportunities to be together.

Once a WRM or LHA becomes recognized in her community as a local resource for breast and cervical cancer education and social support, her position is enhanced, and she will feel a sense of pride in the program.

SPECIAL ISSUES

The purpose of this section is to alert you to issues that may pose special challenges as you develop your Witness Project®. They did indeed pose special challenges for us.

After studying this chapter, you should be able to discuss issues related to:

- 1. Confidentiality
- 2. Literacy
- 3. Transportation
- 4. Hospitals & Physicians
- 5. Acceptance
- 6. Screening guidelines
- 7. Mammography
- 8. Frustrations
- 9. Rewards

Confidentiality

It is vital that your team members maintain confidentiality. When team members have knowledge of intimate aspects of someone's life, confidentiality is crucial. Like all health care professionals, your team members must maintain confidence in order to instill trust.

You must ensure that they understand that if they talk about people and cases they hear about through the project, that they do so in general terms only --- and without using names.

Their proven discretion over time will be the best means of establishing trust and credibility in the community.

Literacy

Literacy problems are particularly acute in rural areas where school completion rates are often lower. Areas with large minority populations and high rates of poverty have the highest percentages of individuals with limited literacy or low reading levels.

- 10% to 13% of American adults are severely illiterate
- 20% of American adults are functionally illiterate and unable to use reading, writing, speaking, and math skills in everyday situations
- It is estimated that 44% of African Americans are functionally illiterate
- 50% of all Americans age 16 years of age and older struggle with basic reading, math, and critical thinking skills

You won't necessarily know if your team members or program participants have reading problems. Those who have low reading levels seldom volunteer this information, and they tend to hide their deficient reading skills from others --- especially when directly asked about it.

■ Limited literacy is **not** a reflection of low intelligence or an inability to learn.

 Adults with less than a high school education usually read 3 to 4 grades below their grade completion level.

Adults with literacy problems may not use health services because they can't understand the written information and instructions they get from health providers, the media, and other sources.

Role playing between LHA and WRMs on how to answer specific questions can increase their ability to take charge and speak out for themselves in the medical community.

Non-written means of communication --- audio tapes, videotapes, interactive computer programs, and basic listening and talking interactions --- are particularly important for individuals with low reading levels.

Individuals who read below the 4th grade level may not benefit from **any** conventional written material, no matter how simply written. One-on-one oral instruction may be the most effective, but it is labor intensive and time consuming.

The Witness Project® model requires minimal reading and writing. We use spoken, face-to-face communication, supplemented with some low-reading level materials.

Your program evaluation methods should accommodate low-reading levels and lack of successful test-taking experience.

We have found that an assessment of the participants' knowledge, beliefs, and attitudes may require an oral questionnaire administered by a trained interviewer.

Self-report, pen-and-paper surveys are not effective unless

they are very brief and simple.

Transportation

Transportation is sometimes a barrier to getting women to attend a program, even if it's in their own church.

Many older women never learned to drive, have stopped driving, or don't drive after dark. Women of lower social and economic status may not own a car. Some women may be concerned about driving alone at night or through certain neighborhoods. Public transportation may not be available or women may be afraid to use it by themselves. Discuss this issue with your program host during your planning stage. Churches and service organizations may be willing to send a van to pick up participants or provide other assistance with these issues.

Hospitals & Physicians

You may find yourself in political situations with local hospitals and physicians as your project progresses. Many rural areas have limited access to services for low-income populations. A cancer-screening program can be threatening to the staff of a small rural hospital if they fear a number of uninsured patients will be diagnosed with cancer.

On the other hand, these hospitals don't want a large health-care institution taking their patients from the referral area. And they have learned to avoid sponsored education and screening programs that are really marketing strategies.

Some members of a community may feel threatened by programs that focus on minorities. As project director, it is vital that you gain the support of the local hospital and its doctors. This requires reporting a good description of your plans, perhaps through a group presentation. Point out how collaboration can benefit both parties. For example, if the hospital considers the Witness Project® a partner, the volunteer program can promote the hospital while increasing its own outreach numbers. Involve the hospital staff in the planning process from the beginning and speak directly with the health care professionals who will be involved in your project.

You read in a previous section about limited-literacy issues. Limited literacy is often associated with a lack of self-empowerment.

Individuals with an **external locus of control** feel no self-control over events in their lives, so they may not take charge of their health. You can address limited literacy by suggesting to the medical staff the best way to ask questions of low-literacy patients. For example, instead of asking, "When was your last mammogram?" ask, "When was the last x-ray picture of your breasts taken?" The health care professional may further explain, if necessary, that this is a type of x-ray where the breasts are pressed down on a plastic shelf, one at a time, to get a good x-ray picture.

It is a mistake to assume a patient receives appropriate and timely cancer screening just because she has a relationship with a primary care doctor. Few visits to the family doctor are for health maintenance.

Most are prompted by specific complaints or for followup of chronic illness. Patients often try to combine an acute illness visit with a complete checkup.

The amount of time scheduled for a focused visit isn't adequate for a comprehensive physical evaluation. Therefore the doctor is at high risk for overlooking family history, environmental exposures, and other risk factors. Even appropriate screening examinations, as indicated by the patient's age, can be overlooked when the purpose of the visit is to take care of a specific medical problem.

As a result, patients may leave the doctor's office with a false sense of security about their health status.

Acceptance

The Witness Project® is founded on the basis of peer education and support. If you, as the director or LHA, are not of the same culture or ethnic origin as the community you are serving, you may encounter some resistance.

If you are a Caucasian, working in an African American or Latino community, for example, your motivation may be questioned. History, personal experiences and cultural living conditions continue to slow the healing of races.

Having a "champion" at the community level who is convinced of the program's goals and committed to its expansion, will prove to be beneficial to your project's survival. Actually, two champions are needed, one at the administrative level, and another at the community level working directly with the volunteers.

We have some advice that you may find helpful...

- Respect the norms and practices of the church or community you are working with. If they are different from yours, it only means that they are different, not wrong.
- Ask questions. Ask the pastor about the usual order of worship.

Is there a prayer at both the beginning and end? Do they usually have a song of praise? What refreshments would be appropriate After all, you are a guest in their church.

■ Pay attention to your appearance. Wear dresses, not slacks. Never wear jeans or sleeveless tops. Avoid power suits (red jackets with black skirts).

 Wear simple jewelry or none at all. Never wear a fur coat.

- Use good manners. While you may have received permission to call older co-workers and friends by their first names, always use titles of respect while conducting a program.
- Be yourself. If you were born Caucasian, you will always be Caucasian - same for African American, Latino, Native American and so on. Don't try to model a culture or ethnic group to which you do not belong. It will only divide you more.

Screening Guidelines

LHAs must be familiar with current mammography and Pap test screening guidelines and be able to answer questions about them.

Pap tests and pelvic examination are recommended every year for all females age 18 and over. A Pap test can detect cancer of the cervix early – while it's still easiest to cure.

New scientific evidence has shown that more lives will be saved if women in the forties age group get mammograms every year rather than every two or three years. A mammogram can detect cancer as small as the size of a freckle or the head of a pin.

The American Cancer Society recently updated mammography guidelines to one simple recommendation: women age 40 and over should have a mammogram every year. Women younger than 40 who have a family history of breast cancer should discuss screening mammography with their health care provider.

Mammography Services

Before you begin your project, find out what resources for low cost or free care are available in your area.

Ask local physicians how they manage patients without insurance coverage. Become familiar with your state's Breast and Cervical Cancer Control Program (BCCCP).

A listing of state contacts can be found in Appendix B beginning on page 20. Check with the American Cancer Society or the Cancer Information Service for a list of accredited mammography facilities in your state.

Access to accredited mammography units is a major issue. Accredited units have FDA approval, ensuring that quality mammography is practiced at the facility. The Mammography Quality Standards Act (MQSA) requires that all facilities providing mammography services meet national quality standards in order to operate.

Medicare will not pay for mammograms taken at facilities that do not have FDA approval. Remind women who are on Medicare to check for this approval.

You may have to transport women to accredited facilities or invite visits by mobile mammography vans. Remember that a medical setting can be intimidating. You may find it helpful to use a buddy system that will provide someone to accompany women to their appointments.

Limited finances and lack of insurance are often reasons given for not having a mammogram. Answers to questions you may get regarding payment for mammography include...

■ Some group insurance plans will pay; some will not.

> • Read the benefit summary, talk with the insurance clerk at work, or call the insurance company's customer service number.

- Medicaid covers most outpatient hospital services including mammograms. However, an annual benefit limit does apply to all x-ray services.
- The hospital or mammography clinic will need the Medicaid identification number prior to the performance of any services.
- Refer any questions regarding coverage of mammograms for Medicaid recipients to your state Medicaid office; there should be a toll-free (1-800) number in your state.
- For those with Medicare Part B, effective January 1, 1998, Medicare will pay 80% of the cost of a screening mammogram each year for all Medicare eligible women age 40 and older. Medicare will also help pay for a one-time (baseline) mammogram for women ages 35-39. (You must be enrolled in Medicare Part A to qualify for Medicare Part B.) The Part B deductible requirement (\$100.00 per year) is waived for screening mammograms.
- Medicare will pay 80% of the cost of diagnostic mammograms, but the \$100.00 deductible must be paid. Women who have supplemental insurance may have no out-of-pocket expense.
- Medicare will help pay for diagnostic mammograms as often as a doctor says they are necessary.

> Refer questions regarding coverage of these services for Medicare beneficiaries to your state Medicare office - there should be a toll-free (1-800) number.

- Encourage women who have no insurance to take advantage of Breast Cancer Awareness Month each October. This is a time when mammograms are often offered at a lower cost, especially to women over age 50.
- Low-cost mammograms are also sometimes offered around Mother's Day.
- Contact local hospitals and cancer prevention programs and ask them to let you know when they plan special promotions.
- Check with your state's Breast and Cervical Cancer Control Program (BCCCP) to learn what state programs are available to assist low-income women.
- Women age 50 to 64 who have no insurance may be able to make an appointment for a free mammogram through the local county health department. There are income-eligibility requirements.

There are some distinct differences and reasons for performing a screening versus diagnostic mammogram.

Diagnostic mammograms, also called problem-solving mammograms, are used to diagnose unusual breast changes or evaluate abnormalities detected on screening mammograms. They usually involve more than two x-rays of each breast and a radiologist is usually in attendance.

Diagnostic mammograms are performed on women who have symptoms or physical findings that suggest breast cancer such as a lump, and on those who have a history of breast cancer.

Screening mammograms are routine breast x-rays that are performed on women who have no signs or symptoms of breast cancer. Screening mammograms are done on supposedly healthy breasts. They usually involve only two x-rays of each breast and are done to detect the presence of breast cancer at an early stage.

Pap test & Pelvic Examination Services

A Pap test and pelvic exam are important parts of a woman's routine health care because they can detect abnormalities that may lead to invasive cancer.

In a pelvic exam, the uterus, vagina, ovaries, fallopian tubes, bladder, and rectum are felt to find any abnormality in their shape or size.

The Pap test is a way to examine cells collected from the cervix and vagina, and can show the presence of infection, inflammation, abnormal cells, or cancer.

Answers to questions you may get regarding payment for Pap tests and pelvic examinations include the following:

- Effective January 1, 1998, Medicare Coverage expanded to include a screening Pap test, pelvic examination, and clinical breast examination (CBE) every 3 years for most women and every year for those at high risk.
- Medicare pays the full claim for Pap tests and 80 percent of the claim for pelvic and breast examinations. There is no Part B deductible for these tests.

Referrals

You or your team members may feel it is an ethical dilemma to encourage women to get clinical breast examinations, mammograms, pelvic exams and Pap tests on a regular basis, especially when third-party reimbursement for these services is limited.

We recommend that cancer survivors stress the convenience of breast self-exam (BSE) and the fact that it is free as the first of a 3-step approach to early detection. Most breast lumps are found by women during BSE, and 8 out of 10 lumps (80%) are benign (not cancer). Although women find 80% of breast lumps, some lumps are too small to be felt during BSE or by the doctor during clinical breast examination (CBE).

In Arkansas, we are navigating women who attend our programs and have either requested assistance in obtaining services or have indicated they are not getting screened regularly, to breast and cervical cancer screening services available around the state (see *Program Registration and Navigational Tool* in Appendix A, page 23). We also encourage them to seek care --- even if they have no insurance. Women are referred to mobile mammography vans; comprehensive care clinics; hospitals; local health units; breast centers, and private physician offices. Our Breast Cancer Control Program administered by the Arkansas Department of Health determines eligibility for both the state and federal breast and cervical cancer programs.

In addition, they maintain a list of alternate, low-cost community resources and providers for women who are not eligible for either program.

Although these services are not usually available through

private physicians, many states now have funding from the Centers for Disease Control and Prevention (CDC) to assist women between the ages of 40 and 64 who are income-eligible.

It is evident from discussions with participants, as well as from current research literature, that more continuing education on early-detection and cancer treatment is needed for health care professionals, especially those with a large minority patient practice. Data indicate many women would be more likely to get mammograms if their doctors simply told them to do so.

General Frustrations

The Witness Project® requires an intense amount of time and labor, especially in the beginning. The reason these women have not been reached by cancer education messages is the reason the project works --- Witness sessions are held when team members are available and have free time (which is also generally your free time).

This becomes tiresome for some team members, but if you train enough WRMs and LHAs, you can manage burnout and keep your project going. To achieve the best response, we suggest you avoid scheduling activities during holidays, family reunion times, bad weather months, festivals, or such times particular to your community. Your Community Advisory Board can help you avoid potential scheduling difficulties. They generally know what's going on in the community.

When planning your project, it is important to be explicit about goals --- both short-term and long-term.

Your goals will drive the training, the roles and tasks of team members, and the evaluation of the activities. With a clear definition of goals and impact measures, the project makes the best use of the volunteers and staff, better addresses the communities' needs, and maximizes scarce financial resources.

Like many health professionals working in medically underserved areas, team members experiencing an overwhelming need for services, as well as family and bureaucratic problems, may become frustrated.

There are a variety of ways to support one another:

- Encourage the formation of natural support groups as the program progresses.
- Plan periodic review sessions to ventilate.
- Give special recognition to volunteers.

Regular meetings of the **Steering Committee** are very important in sustaining your project – after all, it represents your survivors and other team members and they are project! This committee provides a safe forum for review of the project by identifying problems and issues and seeking to resolve them – in the best interest of the project.

Developing and following clear operating procedures with your advisory board will address many issues before they become problems.

> The feeling often surfaces that the project's efforts at direct education just aren't reaching enough women --- the problem is too large for the project to address.

When this happens, it's important to remind team members that lives can be saved one at a time and it is difficult to measure how much change and influence they may be having below the surface.

Rewards

In spite of many challenges, *The Witness Project*® offers tremendous opportunities for personal rewards to you and your team.

In Arkansas, *The Witness Project*® demonstrated a significant increase in BSE practice and mammogram usage. (Our original focus and sample size did not allow us to measure any increase in cervical cancer screening practices.)

The research base for *The Witness Project*® included intervention and control groups from the Arkansas Delta region. Women in the intervention and control groups were interviewed at pre-intervention and 6-month followup to assess beliefs, attitudes, knowledge, and practices related to breast and cervical cancer screening.

Of the women over age 40...

- Regular BSE practice increased from 69.8% to 82.0% (p < .0005*)
- BSE in the past month increased from 49.9% to 65.4% (p < .0001*)
- Ever having a mammogram increased from 52.7% to 64.4% (p<.005*)

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> There were no significant changes in control groups that did not participate in Witness Project® programs. The asterisk (*) indicates a statistically significant increase in a McNemar's test for matched pairs.

> Your team members will be empowered by their service as true foot soldiers in the war against cancer. You will find them using their skills and experiences in ways you never anticipated. They will witness one-on-one to women everywhere they go, whenever teachable moments occur.

WRMs and LHAs will visit women in their homes and counsel women too frightened to go to a surgeon for a biopsy following an abnormal mammogram.

In Arkansas, one of the witnesses was contacted by a church where she had spoken and asked to counsel a young woman with thyroid cancer who was considering suicide and refusing therapy because she was confused and didn't understand that excellent therapy was available for her.

If one of your programs draws only 3 women, your team members should not grumble and complain. They'll go in and do their best because they want those 3 women to feel good about the message and about coming to the program. Likewise, because they are willing to take the message to small rural churches, people who have never heard these stories and messages feel good about them and realize the importance of the message.

The witnesses ask each one to spread the word and tell another woman about the program. As Dorothy Ballard, one of the original WRMs says, That which comes from the heart, touches the heart. Reach out and pass it on.

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THE FOUNDATION

The theoretical and conceptual models used to create *The Witness Project*® include PRECEDE, the 4MAT8 System, the Health Belief Model, and Locus of Control. They consider the social and educational environment of the target audience and provide a framework for appropriate expectations of health behavior change. The National Cancer Institute's (NCI) *Theory at a Glance* is available on the Internet. It is a one-stop resource for all of these theories and models. It is much easier to access and use than a shelf of textbooks.

Since 1989, when we developed *The Witness Project*® model, we have looked at 3 additional theories which help explain why our program works ---Transtheoretical Theory, Community Empowerment, and PEN-3. These theories are the foundation of the training program and intervention. After studying this chapter, you should be able to describe the following theoretical models and give examples of applications in the Witness Project® design:

- 1 PRECEDE
- 2. 4MAT System
- 3. Health Belief Model
- 4. Locus of Control
- 5. Transtheoretical Theory
- 6. Community Empowerment
- 7. PEN-3

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PRECEDE

The PRECEDE model highlights health education as a process related to health decisions and practice. PRECEDE is an acronym for *predisposing*, *reinforcing*, and enabling causes in educational diagnosis and evaluation. This theory suggests health education programs are most effective when they address factors that may predispose, reinforce or enable a behavior.

During the pilot phase of *The Witness Project@*, considerable groundwork was done to diagnose educational and organizational factors that may predispose, reinforce, or enable African American women to go for cancer screening and medical care.

We learned that knowledge and awareness need to be heightened and social norms don't predispose women to early detection practices.

We also learned the church is an appropriate setting to reinforce the desired behaviors --- and mothers, daughters, and grandmothers can encourage each other to continue their new behaviors.

References: Green LW, Krueter MW, Deeds SG, Partridge KB: <u>Health Education Planning: A Diagnostic Approach.</u> Palo Alto, CA: Mayfield Publishing Co., 1980.

Green L, Kreuter MW. Health Promotion Planning: An Educational and Environmental Approach. Mountainview, CA: Mayfield, 1991

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4MAT® System

The Witness Project® role model intervention was based on a theoretical education model, the 4MAT® System. The 4MAT® System is an open-ended teaching method to demonstrate why some methods work with some learners but not with others.

Based on research from the fields of education, psychology, neurology and management, the 4MAT® model offers a way to organize educational material systematically in the *cycle of learning*.

By using teaching techniques that appeal to each of the learning styles, the learning situation becomes more comfortable and understandable for the different learners.

There are 2 major differences in how we learn. The first is how we perceive or experience. In new situations, some of us sense and feel our way, while others think things through. The second is how we process or function.

Learners can be categorized into 4 generalized groups. According to Bernice McCarthy, in her book The <u>4MAT® System</u>, more females (58%) are Type One and Type Four. These types learn best by sensing and feeling.

<u>Female</u>	<u>Male</u>
25% Type One	27% Type Two
33% Type Four	15% Type Three

Type One Learners perceive by sensing/feeling and process by watching/reflecting

They emphasize personal meaning and their preferred method of learning uses discussion and interaction. Their favorite question is why?

Positive learning situations for Type Ones include:

- small group discussion
- a personal relationship with a caring instructor
- creative assignments with guidelines and rules

Negative learning situations include:

- hands-on projects and experiments
- impersonal lessons
- very little thinking time

Type Two Learners perceive by thinking/reasoning and process by watching/reflecting. They emphasize knowledge and prefer the informational method of learning. Their favorite question is *what?*

Positive learning situations for Type Two learners include:

- a well-organized talk
- specific assignments, detailed information
- quiet time before being asked to share thoughts

Negative learning situations:

- few guidelines
- open-ended assignments
- group presentations, role playing
- instructors who get off of the subject

Type Three Learners perceive by thinking/reasoning and process by doing/trying. They emphasize application and prefer the coaching method of learning.

Their favorite question is how does it work?

Positive learning situations for Type Threes include:

- projects with real-life applications
- well-organized assignments that make sense
- hands-on activities

Negative learning situations:

- group work
- discussions about feelings
- restricted learning locations

Type Four Learners perceive by sensing/feeling and process by doing/trying. They emphasize personal adaptation and prefer the self-discovery method of learning. Their favorite question is if? Positive learning situations for Type Fours include:

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- exercises with opportunities for adding their ideas
- giving reports to a group
- creating skits or videos

Negative learning situations:

- rigid, same routines
- no humor
- step-by-step rules or procedures

Within each learner groups are right brain learners, left brain learners, and integrated learners. According to Bernice McCarthy (<u>The 4MAT® System</u>, 1987), 48% of women favor the right mode and 44% favor the left.

Right-brain learners put information together to reach proper conclusions, but have no idea how they processed the data. They find patterns and similarities. Often they are freely emotional and respond better to demonstration than instruction.

Right-brain learners love to participate with Spontaneous vim and vigor; they hate sequencing data

Left-brain learners handle instruction well. They exhibit logical, planned, structured, and analytic behavior. They see cause-effect in a sequential controlled way; they practice emotional control.

They compare differences and remember and think more in language than image. Left-brains look for the experts to provide organized amassed data.

Integrated learners take advantage of the best in both right and left brain worlds. They tend to apply whichever mode best fits a situation.

When all 4 learning styles are taught, alternating from right to left-mode information processing, learners will be comfortable some of the time and stretched and challenged at other times.

All learners need all segments of the cycle in order to keep and use the information. All learners will shine at different places in the learning cycle, so they will learn from each other.

The educator's role changes as she moves through the cycle of learning.

Here's how *The Witness Project*® **training program** proceeds through the 4MAT® cycle of learning:

Step	Question	Mode	4MATKO System	Training Activity
1	Why?	Right	Create an experience.	Connect participants with each other through their stories.
2	Why?	Left	Reflect and analyze the experience.	Ask the participants why are they here.
3	What?	Right	Integrate reflections into concepts.	Show the video so participants can visualize the project.
4	What?	Left	Develop concepts and skills.	Teach the facts about the project and about cancer.
5	How?	Left	Practice facts.	Practice storytelling and BSE so learners can apply what they've learned.
6	How?	Right	Practice and add something of one's self.	Develop original applications for the new knowledge by enhancing stories and explaining BSE.
7	What it?	Left	Analyze for relevance and usefulness.	Practice as a team so participants can share what they have learned and discuss its relevance to the project.
8	What if?	Right	Do it and share with others.	Rehearse a witness program so participants can apply their new knowledge and skills to a more complex experience.

> Traditional schools were designed to teach your left brain. They had to be organized --- sit in your assigned seat, line up, follow the rules. Teachers told you what to learn and how fast to learn it, and then they measured how well you learned. Imagination and creativity (your right brain) were suppressed. This traditional style appeals to only about one-fourth of the population --- the Type Twos.

Many individuals without formal educational backgrounds are right-brain processors who learn best from demonstrated instructions in an open-ended setting that includes auditory effects and emotional judgments. The setting needs to be collegial, participatory, and visual.

References: McCarthy B, Morris S: The 4MAT® System. Chicago: Excel Inc., 1992.

Friedman P, Alley R: Learning/Teaching Styles: Applying the Principles. Theory Into Practice 23:77-81, 1984.

Carbo M: Research in Learning Style and Reading: Implications for Instruction. Theory Into Practice 23:72-76, 1984.

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Health Belief Model

The Health Belief Model (HBM) is based on the theory that people have sets of values, including health values, and they will decide logically how to achieve them.

In the 1950s Hochbaum, Rosenstock and others who were concerned with the limited success of various public health service programs, used motivational theory in an attempt to understand why individuals would not participate in programs to prevent or detect disease.

The resulting HBM has been one of the most influential and widely used psychosocial approaches to explaining health-related behavior.

The HBM asks potential users of health services if they feel they are susceptible to an illness, if the illness has serious consequences, and if care will reduce susceptibility to the disease or reduce its seriousness. If so, is the cost in money, time, trouble, or embarrassment worth the reduced risk? What prompts them to take action? Perhaps a friend had a similar problem, or an advertising campaign pointed out the risk. How motivated is the person to maintain health?

The HBM consists of 3 distinct phases that lead to an action related to health:

- 1. individual perception
- 2. modifying factors
- 3. likelihood of action

The likelihood a person will take a preventive health action depends on perceived benefits of the action, minus the perceived barriers or costs of the action.

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At a Witness program, a woman is shown, through the stories of other women she identifies with, she is *susceptible* to cancer... that is a *serious* illness she could develop. The *benefits* of early detection are to find it early, when a cure is more likely and treatment may be less severe, . . . with a free or reduced *cost* mammogram or pelvic exam and Pap test.

Then she will respond to suggestions and comments from other members of the audience, her family or her physician, or to brochures and other reminders that are *cues* to get the screening and . . . she will be *motivated* to make a positive behavior change. *The Witness Project*® application of this model is illustrated on the next page.

Questions	Perceived Benefit	Witness Project® Application
Susceptible?	Family history may make her feel at risk	Show the learner, through the stories of other women she identifies with, she is susceptible to cancer
Serious?	Disease can cause death or other serious consequences and she could develop the disease	which is a serious illness she could develop.
Benefits?	Threat could be reduced	The benefits of early detection are to find it early, when successful treatment is more likely and less severe.
Cost?	Must be acceptable	with a free or reduced cost mammogram or Pap test.
Cues?	Prompt her to take action	Learner will respond to cues - suggestions from the audience, her family or physician or magnets and brochures, or other reminders to get the screening and
Motivated?	Make a positive behavior	she will be motivated to make a positive behavior change.

References: Janz NK, Becker MH. The Health Belief Model: A Decade Later. <u>Health Education Quarterly</u>. 1984, 11:1-47.

Becker MH, Haefner DP, Kasl SV. <u>Selected Psychosocial Models and Correlates of Individual Health-related Behaviors.</u> Med Care. 1977: 15:27-46

Kirscht JP. <u>The Health Belief Model and Predictions of Health Actions.</u> In: Gochman DS (EDS). Health Behavior. New York: Plenum Press, 1988, pp. 27 - 41.

Glanz K, Lewis FM, Rimer BK (eds). <u>Health Behavior and Health Education:</u> <u>Theory</u>, Research and Practice. San Francisco: Jossey-Bass Publishers, 1990, p 27.

Locus of Control

Locus of control is a behavioral concept that measures people's feelings about their ability to influence or control their lives. The way people believe they are able to change or control their behavior has a major impact on their willingness or ability to comply with medical treatment.

Individuals with an internal locus of control see themselves as in charge of their own health. A patient with an internal locus of control might say, "I have cancer."

Individuals with an external locus of control believe others are responsible for their health --- their physician is responsible for their care, their spouses are responsible for what they eat and others for their stress. The patient with an external locus of control might say, "The doctor says I have cancer."

The patient with an external locus of control is less inclined to comply with prescribed treatment.

Other individuals with external locus of control believe their health is controlled by fate, chance, or God's will. These people feel less self-control over events in their lives, so they often do not take charge of their health situations. "If I get cancer, I'm just going to die, so I'd rather not know."

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Individuals with low literacy often exhibit low selfesteem and external locus of control. Their life-styles center around negative thinking processes as a selffulfilling prophecy, which is repeatedly reinforced by experiencing insults to their personal dignity.

Witness messages encourage women to make their own health a priority, to act assertively with physicians, and to take responsibility by practicing early detection behaviors. Women who are credible messengers, whose life experiences demonstrate the effectiveness of taking control of their health, encourage and empower participants --- even if this historically has not been their tradition or method.

Presenting these programs in church helps women accept the message as more than a secular call for action. The project becomes a special ministry, perceived as part of God's work, in cooperation with God's will. In this way, behavior change becomes more acceptable to women and does not require a change in beliefs.

References: Wallston BS, Wallston KA. Locus of control and health: A review of the Literature. <u>Health Ed Mono.</u> 1978; 6:107-117.

Trans-theoretical Theory

The Trans-theoretical model was developed by Prochaska and colleagues to explain the stages an individual goes through to change health behaviors, including smoking cessation, weight control, substance abuse management, and psychological stress reduction.

Currently, researchers are investigating the use of this theory as it applies to screening behavior.

The model suggests people move through a series of motivational and behavioral stages over time.

The model begins with precontemplation --- when the behavior is not even thought about --- and proceeds through stages of change from contemplation through maintenance, and sometimes relapses.

Transtheoretical Stages of Change

precontemplation
contemplation
determination
action
maintenance
relapse

person is not considering the behavior person is moving toward change making a serious commitment to change is beginning a specific change keeping up the beneficial change person escapes to original behavior

Examples: A woman who has never talked to anyone about breast cancer (pre-contemplative level) may begin talking to her mother, sister, daughter or friend about breast cancer screening or treatment issues (contemplative level) following her attendance at a Witness Project8 program.

A woman who is aware of the need for breast cancer screening (contemplative level), may discuss *The Witness Project*® program messages with her minister's wife following a program, then actually make and keep an appointment for a mammogram (action level).

A woman who has had a mammogram several years ago (relapse level), may decide that it is time to have another mammogram, and even begin having one annually (maintenance level) after hearing the Witness volunteers at her church.

Training activities to move women from precontemplation to contemplation are illustrated on the next page. Many rural African American women are at a contemplative level of change. At this level, they require consciousness-raising, dramatic relief, and environmental re-evaluation in an intervention program.

Activity	Objective	Methods	Witness Project®
Consciousness-raising	Increase learners information about the health problem.	Observation Confrontation Interpretation Literature Videotapes	 Tell cancer stories Discuss beliefs, such as It couldn't happen to me! Show cancer happens to other black women like themselves (not just celebrities). Confront and interpret issues to raise knowledge and awareness levels.
Dramatic relief	Enable learners to experience and express feelings about their problems and solutions.	Psychodramal Role play	Present emotional and sometimes humorous experiences to dramatize importance of finding cancer early in order to survive. Express fears, emotions, and spiritual beliefs related to cancer and the screening process. Discuss issues one-on-one with survivors.
Environmental re-evaluation	Permit learners to assess how their problems affect the physical environment.	Training Documentaries	 Deliver facts about cancer incidence in black population. Stress importance of early detection. Encourage learners to take care of themselves. Influence and change social norms by presenting information to family members and friends together.

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> The model is circular rather than linear. A person can enter or exit at any stage. The action phase takes about 6 months, and maintenance can last 2 to 3 years.

> Transtheoretical theory moves beyond the Health Belief Model constructs to include variables of environmental influences and barriers to action. Scales to measure levels of change in screening behaviors are being tested.

If you know where members of your audience are, you know where to start. Many medically underserved African American women, particularly those from rural areas, are in the *precontemplation* stage.

Precontemplators process less information about their problems, devote less time and energy to evaluations of themselves or their behaviors, and generally experience fewer emotional reactions to any negative aspects of their problems.

Interventions, like mammography screening, aren't effective with women in the precontemplative stage. If a woman hasn't started thinking about being at risk for breast cancer, there is no point in giving her detailed information about making an appointment for a mammogram. It would be better to raise her consciousness regarding cancer risk and the benefits to be achieved from early detection.

References: Prochaska JO, DiClemente CC: Stages and Processes of Selfchange of Smoking Toward an Integrative Model of Change. J Consulting and Clinical Psych 51:390-395, 1983.

Prochaska JO, DiClemente CC, Norcross JC: In Search of How People Change, Aplications to Addictive Behaviors. American Psychologist 47: 1102-1114,

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1992.

Community Empowerment

Health promotion is more successful when the community identifies its own health concerns, develops its own prevention and intervention programs, forms a decision-making board to make policy decisions, and identifies resources for program implementation.

Community empowerment concerns the active involvement of disenfranchised persons in governance and decision-making processes that impact quality-of-life issues. It is based on concepts of self-determination, shared decision-making, bottom-up planning, community problem solving, cultural relevance, and debunking or blaming of victims' syndrome. It involves developing community leadership for health promotion and advocates for community health promotion and development of supportive interpersonal relationships.

The Witness Project® can be an effective community empowerment program in several ways. The Community Advisory Board is a mechanism for developing and promoting community leadership. Major forces for community change are Witness Role Models and Lay Health Advisors. The local community can assume ownership of the project. When a Witness Project® is truly a grassroots effort, it has the greatest chance of changing behaviors and continuing over time.

To foster community empowerment, you should seek the involvement of influential community members, and even survivors, *before* initiating your project.

The community should play a strong role in the design and nature of the project in order to feel ownership.

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Witness Project® activities should be developed from within and not offered to the community from outsiders.

PEN-3 Model

In 1992, Airhihenbuwa proposed the PEN-3 model for planning and developing culturally appropriate health promotion interventions for the African American community in the United States. This multi-dimensional model builds on PRECEDE and the Health Belief Model, and was originally developed for use in African countries.

PEN-3 considers the social and educational environment of the population, such as cultural appropriateness of the health behavior and the health education program itself.

Airhihenbuwa stresses the importance of reflecting cultural perspectives and working within the culture and community when offering health education programs. By providing a culturally tailored message through the respected community institution of the church and having community volunteers (rather than health professionals) disseminate the message, the Witness Project® promotes respect for cultural ideas and beliefs. The witness role models' messages are consistent with traditional and spiritual aspects of the lives of the people, and thereby demonstrate respect and understanding for the audience and the community.

The PEN-3 Model

Health Behavior Dimension		Health Education Dimension
Perception	P	Person
Enablers	E	Extended Family
Nurturers	N	Neighborhood
	Positi Exot: Nega	ic

Cultural Appropriateness of Health Beliefs Dimensions

References: Perry CL, Baranowski T. Parcel GS. How Individuals, Environments, and Health Behavior Interact: Social Learning Theory. In: Glanz K, Lewis FM, Rimer BK (eds). Health Behavior and Health Education San Francisco: Jossey-Bass Publishers, 1990,, pp. 161-186.

Michielutte R, Dignan MB, Wells HB, et al: Development of a Community Cancer Education program: The Forsyth County, NC, cervical cancer prevention project. Public Health Rep 104:542-551, 1989.

Bandura A. Social Learning Theory. Englewood Cliffs, NJ: Prentice-Hall, 1977

Reference: Airhihenbuwa CO: Health promotion and disease prevention strategies for African-Americans: A conceptual model. In: Braithwaite RL, Taylor SE, Editors, Health Issues in the Black Community. San Francisco: Jossey-Bass Publishers; 1992:267-280.

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In this section are forms to help you design, implement and evaluate your Witness Project®. Each full-size form is preceded by a cover sheet explaining how, when and by whom the form is to be completed.

If your Witness Project® is participating in the national replication and dissemination (R&D) grant, the Informed Consent Form, Program Registration Form, Follow Up Sheet, and Progress Report must be used for reporting. The title of each required form is followed by a ✓ as a reminder. The remaining forms, may be photocopied to gather data at the local level, or used as models to develop your own forms.

The forms are also available on a diskette, formatted in Word and on CD-ROM.

Implementation Checklist

A checklist is provided to assist you in developing your Witness Project®. Sequential tasks for preparation in setting your foundation, recruiting and training team members, presenting your first program, and maintaining your project are identified.



THE WITNESS PROJECT® Implementation Checklist

PREPARATION

	A Trademark Licensing Agreement has been signed by the sponsoring organization and returned to The <i>Witness Project</i> ® national office.
	The mission of <i>The Witness Project</i> ® has been determined to be compatible with the mission of the sponsoring organization.
	A Project Coordinator has been identified.
	An operating budget has been determined, including funding sources and in-kind contributions.
	The Project Coordinator has read all sections of the Implementation Guide, including appendices.
	The Project Coordinator has viewed the videos included in the Implementation Guide.
	☐ The Witness Project® Facilitator video "Witnessing To Save Lives"☐ If I Can Help Somebody
	☐ Lange BSE video
	A Community Advisory Board has been organized.
	A Training Coordinator (if different from the Project Coordinator) has been identified.
	Memorandums of Agreement with <i>The Witness Project</i> ®, local Breast, and Cervical Cancer Control Program and/or other collaborators have been signed.
	A plan for navigating women to obtain clinical (screening) services is in place. Human Subjects approval and informed consent issues, if applicable, has been
_	resolved.
	Resources to secure breast models, audio-visual equipment, and program materials have been identified.
	Technical assistance needs from <i>The Witness Project</i> ® national staff have been assessed and, if necessary, arranged.
RECR	RUITMENT OF TEAM MEMBERS
-	Potential sources to identify team members have been identified and approached. Witness Role Models (survivors) have been recruited (2 for minimum level programs, 4 for moderate level programs, and 10 for regional or state level programs).

	Lay Health Advisors (peer educators) have been recruited (1 for minimum level programs, 3 for moderate level programs, and 5 or more for regional or state level programs).
	Applications have been completed on all recruited team members.
	A Steering Committee of team members has been organized. The purpose of the Steering Committee has been clearly communicated to volunteers.
TRAI	NING OF TEAM MEMBERS
	The Training Coordinator has read the training curriculum.
	The Training Coordinator has reviewed the videotapes, overhead transparencies and/or slides that will be used.
	The Project Director/Coordinator and Training Coordinator have met to discuss the training format.
	The following logistics in conducting the training have been completed: Convenient date for team members selected.
	☐ A training room with an additional breakout area has been secured.
	Audio-visual equipment has been secured.
	□ VCR and monitor
	☐ Overhead projector☐ Slide projector
	☐ Slide projector ☐ Menu for meals and snacks has been identified.
	Invitations to the training have been mailed to recruited team members.
	Transportation and lodging assistance have been secured.
	Training manuals have been assembled for:
_	☐ Witness Role Models
	☐ Lay Health Advisors
	Telephone confirmations have been made with recruited team members the week
	of the training.
	On the day of the training, the room is prepared with:
	☐ Manuals
	□ Name tags
	☐ Audio-visual equipment
	Breast models
	Forms for travel reimbursements
	Pre- and Post-Tests
	Certificates of completion
	Refreshments
	Participants have completed a training session evaluation.
	Trainers have completed a self-evaluation of their performances.
	Travel forms have been given to the Project Coordinator Evaluations of the training session have been given to the Project Coordinator to
_	Evaluations of the training session have been given to the Project Coordinator to forward to the Evaluation Coordinator.
	iorward to the Evaluation Coordinator.

SCHEDULING YOUR PROGRAMS

	A plan for marketing The Witness Project® to the community has been
	developed.
	Availability of team members has been determined.
	Arrangements have been made for the following:
	Brochures
	Breast forms
_	□ VCR and monitor
	Transportation needs of team members have been identified and resolved.
	Appropriate forms have been tailored (if necessary), copied and given to team
	members:
	☐ Sign-in sheet
	Program Registration & Informed Consent Forms
	Activity Reports Travel Reimbursement
	☐ Prompt Card
	Confirmation has been made with the hosting church or organization.
	Thank-you letters will be sent after the programs.
25.172	WILL DAVING MONTH DECEMBER
MAIN	TAINING YOUR PROJECT
	Decider meetings with toom members are planted for continuing education and
	Regular meetings with team members are planned for continuing education and
	fellowship. The Community Advisory Board has been undeted
	The Community Advisory Board has been updated.
Ч	The Project Coordinator has developed a schedule for collecting and logging
	activity reports, Sign-in-sheets, Program Registration Forms, Informed Consent
	Forms, and training evaluations. A system is in place for Navigation of Services for women who request assistance
ч	and who may be eligible for free or low-cost breast and cervical cancer screening
	services.
	Demographic and program data (Progress Report) regarding Witness Project®
	(WP) activities is sent to the Evaluation Coordinator every other month.
	The WP site participates in conference calls with WP Replication &
_	Dissemination (R&D) staff within 2 weeks of submission of the Progress Report.
	Expanded sources of funds and in-kind resources have been identified.

Sign-In Sheet

Program participants sign this sheet before a Witness program begins. Encourage each participant to provide complete information. Ages and telephone numbers are important for completion of follow-up contact. You may need to edit the ethnicity boxes to reflect your participants. For instance, if your project serves ethnic groups from the Caribbean or more recent immigrants from African nations, you will want to designate their ethnicity or "African Descent."

Ideally, the Witness Role Model (WRM) or Lay Health Advisor (LHA) who plans the program is responsible for collecting the sign-in sheet. In smaller or newly developed programs, the Project Director/Coordinator may attend each program and collect this sheet.

Sign-in sheets for each program should be given to the project director, who will use them in documenting the activities of your Witness Project®.

Informed Consent ✓

If your Witness Project® is collecting data for evaluation, which includes individual identification or confidential medical record information (such as mammography reporting or impact), you will need to get approval from a Human Subjects review mechanism such as an **Institutional Review Board** (IRB). You may qualify for an exemption as an educational program. If you determine that written informed consent is required, tell your participants that they are being asked to complete an *Informed Consent Form.* This consent form gives you permission to contact them at a later date to help them obtain any services for which they have requested assistance on the Program Registration Form (whether or not they are eligible). Also tell them that this does not affect their participation in the Witness program. Anyone can participate in the educational program.

The *Informed Consent Form* is distributed along with the *Program Registration Form*, to the entire group after the Lay Health Advisor (LHA) cites breast and cervical cancer facts and resources. Consenting participants can take the top page with them for later review. Allow time for questions and clarification of the consent form.

Emphasize...

- Their participation will help determine how to best assist women to obtain life-saving breast and cervical cancer screenings.
- Participation is voluntary.
- There are no known risks to individuals as a result of participation.

■ Within one week of the Witness program a Witness Project® representative will contact those participants who have indicated they are not getting regular screenings and those who have requested assistance in obtaining screening services (see Program Registration Form in this Appendix). A Witness representative will again contact them within one month after their scheduled appointments.

All information is confidential. No names, addresses, or telephone numbers will be shared with any other organization without expressed consent. Reporting will be by group only.

You should customize information about local participation, contact persons and telephone numbers as appropriate for your Witness Project® program on your consent form.



THE WITNESS PROJECT® CONSENT FOR FOLLOW-UP CONTACT

You are invited to participate in an educational program that encourages early detection and screening practices for breast and cervical cancer. The study is being conducted by The Witness Project®, the Arkansas Cancer Research Center, and the University of Arkansas for Medical Sciences (UAMS), and (local organization/institution). Thousands of women across the nation have already participated in this program, and vou were selected as a participant in this study because you live in (city/state/local), are at least 20 years of age, and are willing to learn about breast and cervical cancer screening. This program will empower you to take a more active role in ensuring better breast and cervical health for yourself, and the results will give researchers valuable information that will help provide better health care for women.

As a volunteer participant in this study, you will be asked to listen to speakers and learn how to perform breast self-examination (BSE), including the use of synthetic breast models for demonstration, as well as information about having clinical breast examinations, mammograms, pelvic examinations, and Pap tests. The program will take approximately 1½ hours. About one week after the program, we may call you to help you get the services indicated on the Program Registration Form. During this fifteen-minute telephone call, you may receive information about organizations that provide free and low-cost pelvic examinations, Pap tests, clinical breast exams, mammograms, transportation, and other services. Witness representatives may perform a follow-up telephone call within one month to verify you received services. By signing the Program Registration Form provided at the Witness program, and by signing this informed consent, your name, address, and telephone number may be given to a local agency to help you obtain some of the free or low-cost screening services.

Your responses will be kept strictly confidential. The information is for referral and study purposes only. Any information from this study will be reported by group form only. You will not be identified by name or by any information you give us. Your personal information will never be released to any company, so nobody will call you to sell you anything. The only people who may ever see your personal information is the University of Arkansas for Medical Science's Human Research Advisory Committee, who make sure you are protected from unapproved research. Participation in this study is voluntary, and you may end your involvement with any part of this program, or the entire program at any time. Your participation in the research study may be terminated without your consent. There are no risks to you as a participant. If you choose not to participate in the study it will not affect any benefits or treatments you will receive. Signing this consent form does not mean that you are obligated to participate in any other research protocol or treatments. It only means that you are giving permission to be contacted. By signing this consent form you will not waive any legal right to which you are legally entitled. No monetary compensation will be provided to you, and you may not receive any benefit from this program.

If you have any questions regarding this study or need further assistance with breast and cervical cancer screenings, you may ask a Witness Project® representative at the time of the program, call the Arkansas Witness Project® state office at 1-800-275-1183, contact the national Principal Investigator, Deborah O. Erwin, Ph.D. at 501-526-6676, or your local representative, (local contact and phone number). If you have any questions about your rights with respect to your involvement with this educational program, or related injuries, please contact the UAMS Institutional Review Board at (501) 686-5667.

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This page is for The Witness Project® participants to complete, and will be collected by a Witness Project® representative. The first page should be kept by the participant for any future use.

I have read the previous statement or someone has read it to me. I have been able to ask questions and express concerns, and I have received a satisfactory response by a representative of The Witness Project® or the investigator. I understand the purpose of the program as well as the potential benefits that are involved. I hereby give my informed and free consent to be a participant in this program.

Participant's Signatur	Participant's Signature		
Witness Project® Rep	resentative's Signature	Date	
Principal Investigator:	Deborah O. Erwin, Ph.D., CTR Associate Director of Education Associate Professor, Surgical Onco	Date	

Expense Form

If your Witness Project® decides to reimburse volunteers for expenses or mileage, you will need a form for requesting payment.

In Arkansas, we provide the WRMs and LHAs a stipend depending on the length of the program. Mileage is reimbursed at \$.29 per mile over 40 miles. The request for reimbursement is then forwarded to Area Outreach Coordinators for submission to our Witness Project® program office.

The reimbursement process is one that you may have to create according to your own needs. The Arkansas Witness Project® WRMs and LHAs submit their expense forms monthly, but their requests are held until expenses total \$40.00. Be sure to talk with your financial officer to clarify that your budget contains a line item for stipends and other expenses, and determine what information may be required for an audit.

If you choose to use the process described in the above paragraphs, you may use the form as is. Space has been provided for you to insert the appropriate name and address to where the form should be returned.

You also may want to consider other incentives (purely optional) for your team members for the programs they conduct, such as giving them debit cards for department stores, mall gift certificates, or hosting an awards luncheon to recognize them for their program activity. There are many creative ways you may use to encourage team members to keep active and continue the work to spread the news about early detection. These incentives serve to keep team members motivated and may help offset some household expenses.

The Witness Project®



THE WITNESS PROJECT® **Expense Reimbursement Form**

I	NAME:		TELE	PHONE:			
1	ADDRESS:						
\$	SOCIAL SECURITY #:		CAR TAG (DRIVER ONLY):				
	This form is to be completed by each WRM or LF program is \$20.00 (0-6 hours in length) and \$40.00 may not accumulate mileage. Try to car pool whe <i>reimbursement (no exceptions)</i> . Forms should be	of for a program that exceeds 6 hours. You enever possible. Attach original receipts for	will be paid \$	8.37 per mile for trips of	40 miles or more. You		
DATE	LOCATION, CITY, AND COUNTY	TYPE OF PROGRAM (WP PROGRAM, HEALTH FAIR, OR TRAINING PROGRAM)	HOURS	MILES (ROUND TRIP AND ONLY IF YOU DROVE YOUR CAR)	REIMBURSEMENTS (ATTACH RECEIPTS)		
	Number of programs @ \$40.00 Miles @ \$.37 per mile Total reimbursements	=	DATE	E SUBMITTED:			
					©2000		

Progress Report ✓

Using the information from the Sign-in-sheets, Program Registration Forms, training evaluations, and other program development and implementation activities, the Project Director/Coordinator is responsible for completing the Progress Report. This information is used to determine how well your project is progressing, whether or not technical assistance is needed, and to share your successes and challenges,

The initial Progress Report is due no later than the 10th day of the third month after your site has been selected to be a Witness Project® replication site and every other month thereafter. There may be nothing to report other than the preparation to get your Witness Project up and running, such as orientating any additional administrative staff, recruiting more Witness Role Models, making community contacts for programs, or getting your educational materials and breast models ordered.

Very shortly (about 2 weeks) after we receive your Progress Report (and all subsequent Progress Reports for the duration of the grant period), a conference call will be set up between *The Witness Project*® replication team and your Witness Project® administrative staff (Project Director and /or Coordinator(s). This would be the time to share your successes and / or discuss any issues or concerns the replication staff may be able to assist you with. Using the Monthly Activity Report on page 8 in this Appendix may assist you in keeping track of your activities for reporting purposes.

	THE WITNESS PROJECT® PROGRAMS CONDUCTED							
DATE	COMMUNITY SETTING		M SETTING type and/or name)	LENGTH	#OF WRMs	#OF LHAs	TOTAL #	TOTAL # WOMEN
	(Metro, Urban, Suburban, or Rural)	CHURCH	COMMUNITY GROUP					AGE 50+

Monthly Activity Report

A monthly report provides a snapshot view of your program's activities. The reporting record is for internal use only and is included to help you organize information for your progress report.



THE WITNESS PROJECT®

Monthly I	Report for	,19	
	teport for	11/	

DATE	TIME	LOCATION, CITY, AND COUNTY	CONTACT PERSON	#WRMs	#LHAs	TOTAL # WOMEN	

TOTAL # PROGRAMS	TOTAL # PARTICIPANTS	TOTAL # WRMs
101112 // 1110 014 1110	TOTAL # WOMEN 50+	TOTAL # LHAs

The Witness Project®

Expenditure Report

An expenditure report will assist you as you develop an operating budget for your Witness Project®. Under the chapter, *Training* Your *Team* (pages 53 - 56) in this Guide, we have identified supplies that you will need for your program.

The expenditure report also provides space for you to identify any in-kind contributions. Lastly, the report can be used as a guide in developing funding proposal budgets.



THE WITNESS PROJECT® EXPENDITURE ITEMIZATION

PERIOD OF REPORT:		DIRECTOR:			
		BEGINNING BALANCE: \$			
TRAINING		In-Kind Donations:			
-	Refreshments				
-	Stipends				
-	Travel				
-	Supplies				
-	Other (please identify)				
		TOTAL \$			
PROC	GRAM				
-	Breast Models	In-Kind Donations:			
-	Materials				
-	Travel				
-	Publicity/Media				
-	Participant Incentives				
-	Equipment				
-	Team Member Stipends				
-	Other (please identify)				
		TOTAL \$			
STAF	FING AND SUPPORT				
-	Salaries	In-Kind Donations:			
-	Copying				
-	Telephone / Email				
-	Postage				
-	Printing				
-	Other (please identify)				

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	TOTAL \$	
EVALUATION		
Contract	 In-Kind Donations:	
Telephone		
Other (please identify)		
	TOTAL \$	
ENDING BALANCE:	\$	

Annual Report

Like the monthly report, the annual report is for internal use only. It is included to assist you in determining where your program is and where you want it to be in the years to come.

The Witness Project® $$\mathbb{C}$$ 2000 Revised 03/2004



THE WITNESS PROJECT® Annual Report for 20____

MONTH	TOTAL # OF PROGRAMS	TOTAL # WRMs	TOTAL # LHAs	TOTAL WOMEN	TOTAL WOMEN AGE 50+
JANUARY					
FEBRUARY					
MARCH					
APRIL					
MAY					
JUNE					
JULY					
AUGUST					
SEPTEMBER					
OCTOBER					
NOVEMBER					
DECEMBER					
YEARLY TOTAL					

Witness Role Model Application ✓

You will need an application for potential Witness Role Models (WRMs). In most cases, they will have talked with someone beforehand to learn about the Witness Project®.

The application also provides you with a written commitment to participate in the Witness program.

All team members and Witness staff may participate in recruiting potential WRMs and LHAs.

Keep in mind that recruitment for both WRMs and LHAs should be a secondary goal as Witness programs are presented.



THE WITNESS PROJECT® Witness Role Model Application

Name:	
Address:	
City/State/Zip:	
County:	Telephone: (daytime) (evening)
Date of Birth:	!// Social Security Number:
Are you an U.S. Cit	tizen? Yes No If no, list your nationality:
Are you employed?	YesNo If yes, name your employer and normal working
hours:	
Years of school com	pleted: (circle) 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16+
	MEDICAL INFORMATION
Type of capeer:	MEDICAL INFORMATION
Date of Diagnosis:	(month and year)
Date of Diagnosis: Yes No	(month and year) Has your cancer metastasized (spread from the original site)?
Date of Diagnosis: Yes No	(month and year)
Date of Diagnosis: Yes No Yes No	(month and year)
Date of Diagnosis: Yes No Yes No Yes No	(month and year)
`	(month and year)

	ORIENTATION INFORMATION
YesNo	Are you willing to talk about your cancer experiences with other women?
Yes No	Are you willing to participate in 3 to 12 cancer education programs in your area (community) each year?
YesNo	Are you able to attend a total of 8 hours of orientation?
YesNo	Since training will probably take place during evening hours or weekends; do you have a preference? If yes, please indicate your preferences below: Weekday Evening: Monday Tuesday Wednesday Thursday Weekend: MorningAfternoonEvening
YesNo	Are you mobile and able to travel away from your home without any assistance? If no, what assistance do you require?
Yes No	Do you have any child-care or older adult-care responsibilities?
Yes No	If yes, will you be able to make arrangements for those under your care during the time you spend away from home attending training and education sessions?
	e as a Witness Role Model, I understand I will be required to attend g and commit to participate in at least 3 Witness programs per year.
regarding their he	t participants at Witness Project® programs may share information ealth that may be considered confidential. I agree not to share this anyone without their expressed consent.
Applicant's Signa	ture: Date:

COMMENTS

Lay Health Advisor Application

The Lay Health Advisors (LHAs) are also required to complete applications. They too, may have talked to someone beforehand about the Witness Project®.

The LHA application also provides you with a written commitment to participate in the Witness program.

All team members and Witness staff may participate in recruiting potential WRMs and LHAs.

Keep in mind that recruitment for both WRMs and LHAs should be a secondary goal as Witness programs are presented. There is generally a larger recruitment pool for LHAs. Applications may be taken whenever programs and outreach activities are conducted. You may also approach organizations of African American women, such as the Black Nurses Association and sororities, to recruit LHAs. Organizations such as these may view this as part of their community work and help you find the volunteers you need.



THE WITNESS PROJECT® Lay Health Advisor Application

	GENERAL INFORMATION
Name:	
Address:	
City/State/Zip:	
	Telephone: (daytime) (evening)
Date of Birth:	Social Security Number:
Are you a U.S. Cit	izen? Yes No If no, list your nationality:
Are you employe	d? Yes No If yes, name your employer and normal working
hours:	
	ompleted: (circle) 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16+
	TRAINING INFORMATION
Yes_ No_	Have you ever worked as an instructor of some kind (public school, Sunday school, etc), not necessarily for pay?
Yes No	Have you ever done any public speaking (talked before groups of people formally or informally)?
Yes No	Are you comfortable with and do you enjoy talking in front of groups of people?
Yes No	Are you able and willing to participate in 3 to 12 cancer education programs in your area (county) per year?
Yes No	Are you able to attend a total of 8 hours of training?
Yes No	Since the training will probably take place during the evening hours or weekends, do you have a preference? If yes, please indicate your preference below: Weekday Evening. MondayTuesdayWednesdayThursday Weekend: MorningAfternoonEvening

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	Please note other time requirements or restrictions:
Yes No	Are you mobile and able to travel away from your home without any assistance? If no, what assistance do you require?
Yes_ No_	Do you have any child-care or older adult-care responsibilities?
Yes_ No_	If yes, will you be able to make arrangements for those under your care during the time you spend away from home attending training and education sessions?
an 8-hour traini	eve as a Lay Health Advisor, I understand I will be required to attending and commit to observing 3 Witness programs before participating in at all programs per year.
regarding their	at participants at Witness Project® programs may share information health that may be considered confidential. I agree to not share this anyone without their expressed consent.
Applicant's Sign	ature: Date:

COMMENTS

Training Invitation, Reply Form, and Directions

As you organize training events, you will need to send a **letter of invitation** to those who have expressed interest in becoming a team member. Sent by the Training Coordinator or person responsible for training duties, the letter should be mailed at least two weeks before the date of the event. You may also send a letter to organizations that are assisting you in the recruiting of team members or individuals. A sample letter of invitation is provided.

You should enclose a **reply form** in order to make travel arrangements and accommodate any special needs. If the potential WRM or LHA has not completed an application, you may also enclose these forms for return in your reply form as a courtesy. Enclose a **map or directions** to the training site with a telephone number where you can be reached the day of the training.

The samples may be adjusted to suit the needs of your project. Always plan to follow-up with a telephone call the week of the event to confirm attendance. You will want to make sure you have enough training materials and refreshments for your trainees.



SAMPLE

September 05, 2000

Ms. Jane Doe P.O. Box 123 Anytown, AR 76543

Dear Ms. Doe:

Thank you for agreeing to serve as a Lay Health Advisor. We are delighted to have you on board! We appreciate your interest in becoming involved with The *Witness Project®*, a breast and cervical cancer education program which focuses on African American women. Under the auspices of the Arkansas Cancer Research Center (ACRC) at the University of Arkansas for Medical Sciences (UAMS), *The Witness Project®* has become nationally acclaimed. Since its birth in 1990, the project has grown from a hand full to nearly one hundred team members plus staff and has reached almost 4,000 women throughout the state.

Please join us at our next training on Saturday, October 28, 2000, from 8:30 A.M. until 4:00 P.M. at the American Cancer Society (ACS) located at 901 North University here in Little Rock. There is plenty of free parking in front of the building.

Please complete both the Lay Health Advisor application and training attendance form and return them in the enclosed self-addressed stamped envelope by **Friday, October 20th.** It is important that we know your plans as soon as possible. If you prefer, you may leave a message at 1-800-275-1183 or dial Charlie Stayton direct at 501-526-7110. We will begin making confirmation calls on October 23rd.

Thanks again for your desire to become a Witness team member. We are excited about meeting you and welcoming you into our family. See you on the 28th!

Sincerely,

Charlie Stayton, Executive Director *The Witness Project*®

Pre- and Post-Tests

A pretest should definitely be used for Lay Health Advisors at the beginning of the training, before the cancer education portion of the training begins. Witness Role Models (WRMs) in Arkansas do not have to take the test unless they are cross training. However, WRMs may be given the pretest if they elect to take it – **they have the option.**

Since WRMs are telling their story, they are not responsible for learning facts to be able to teach, unless they want to be cross-trained to become LHAs. However, some sites have found that WRMs also act as sources of information in their communities and can benefit from learning the factual information. LHAs should complete the same test at the end of the training (posttest).

Explain that these tests are given to help you determine what should be emphasized during the training and to see if you are successful in presenting information. The tests are not intended to grade or judge the trainees. The scores of the pretest are important as an assessment of what they know before the training. The posttest, however, should be used as an indicator of knowledge gained as a result of the training. Each team member should be able to answer 78% of the questions correctly (11 out of 14 questions). If a trainee scores less than 78%, you should follow-up with her to assess her learning needs.



THE WITNESS PROJECT® Training Pre-Test

NAI	ME:	DATE:				
	Please circle the response that best matches your agreement with each statement. Answer every question, even if you are not sure. Your answers will let us know just what we need to teach you.					
1.	The only way to treat breast cancer is for a surgeon to remove a woman's breast.					
	Yes, I agree	I am not sure	No, I disagree			
2. 1	Mammograms are used to cure breast c	ancer.				
	Yes, I agree	I am not sure	No, I disagree			
3. I	Bruising your breast can cause breast ca	ancer.				
	Yes, I agree	I am not sure	No, I disagree			
	Vomen 40 years old or older should havave any problems.	ve a mammogram every 6 year	s, even if they don't			
	Yes, I agree	I am not sure	No, I disagree			
	f you check your breasts thoroughly every	ery month, you don't need to g	get a mammogram once			
	Yes, I agree	I am not sure	No, I disagree			
6. E	Breast cancer lumps are much more trea	table when found early.				
	Yes, I agree	I am not sure	No, I disagree			

7.	Mammograms are mainly good for women who feel a lump in their breast or have some other symptoms.		
	Yes, I agree	I am not sure	No, I disagree
8.	Exposing breast cancer to the air	during surgery can cause can	cer to spread.
	Yes, I agree	I am not sure	No, I disagree
	The amount of radiation a woman riding in an airplane.	gets from a mammogram is	less than what she gets from
	Yes, I agree	I am not sure	No, I disagree
10.	Mammograms can find breast lun	nps that are too small for doct	tors to find.
	Yes, I agree	I am not sure	No, I disagree
11.	More African American women g	get breast cancer than white w	omen.
	Yes, I agree	I am not sure	No, I disagree
12.	More African American women d	ie from breast cancer.	
	Yes, I agree	I am not sure	No, I disagree
13.	A 55 year-old woman has a highe	r chance of getting breast can	cer than a 35 year-old woman.
	Yes, I agree	I am not sure	No, I disagree

Master Key



THE WITNESS PROJECT®

Training Pre-Test

NA	ME:	DATE:		
	ase circle the response that best matches not sure. Your answers will let us know		nt. Answer every question, even if you	
1.	The only way to treat breast cancer is	for a surgeon to remove a woman's l	breast.	
	Yes, I agree	I am not sure	No, I disagree	
2.	Mammograms are used to cure breast	cancer.		
	Yes, I agree	I am not sure	No, I disagree	
3 .	Bruising your breast can cause breast c	eancer.		
	Yes, I agree	I am not sure	No, I disagree	
4.	Women 40 years old or older should have a mammogram every 6 years, even if they don't have any problems.			
	Yes, I agree	I am not sure	No, I disagree	
5.	If you check your breasts thorou a year.	ughly every month, you don't n	need to get a mammogram once	
	Yes, I agree	I am not sure	No, I disagree	
6.	Breast cancer lumps are much n	nore treatable when found early	7.	
	Yes, I agree	I am not sure	No, I disagree	

Master Key

7.	Mammograms are mainly good for women other symptoms.	n who feel a lump in their breast o	or have some
	Yes, I agree	I am not sure	No, I disagree
8.	Exposing breast cancer to the air during s	surgery can cause cancer to spread	d.
	Yes, I agree	I am not sure	No, I disagree
9.	The amount of radiation a woman gets from	om a mammogram is less than wh	at she gets from riding in an airplane.
	Yes, I agree	I am not sure	No, I disagree
10.	Mammograms can find breast lumps that	are too small for doctors to find.	
	Yes, I agree	I am not sure	No, I disagree
11.	More African American women get breas	st cancer than white women.	
	Yes, I agree	I am not sure	No, I disagree
12.	More African American women die from	breast cancer.	
	Yes, I agree	I am not sure	No, I disagree
13.	. A 55 year-old woman has a higher chance	e of getting breast cancer than a 3:	5 year-old woman.
	Yes, I agree	I am not sure	No, I disagree



THE WITNESS PROJECT® Training Post-Test

NA	AME:	DATE:				
	Please circle the response that best match your agreement with each statement. Answer every question, even if you are not sure. Your answers will let us know just how well we taught you.					
1.	. The only way we have to treat breast cancer is for a surgeon to remove a woman's breast.					
	Yes, I agree	I am not sure	No, I disagree			
2.	Mammograms are used to cure	e breast cancer.				
	Yes, I agree	I am not sure	No, I disagree			
3.	Bruising your breast can cause	breast cancer.				
	Yes, I agree	I am not sure	No, I disagree			
4.	Women 40 years old or older shave any problems.	should have a mammogram every	6 years, even if they don't			
	Yes, I agree	I am not sure	No, I disagree			
	If you check your breasts thora a year.	oughly every month you don't ne	ed to get a mammogram once			
	Yes, I agree	I am not sure	No, I disagree			
6.	Breast cancer lumps are much	more treatable when found early.				
	Yes, I agree	I am not sure	No, I disagree			

7. Mammograms are mainly good for women who feel a lump in their breast or other symptoms.		their breast or have some	
	Yes, I agree	I am not sure	No, I disagree
8.	Exposing breast cancer to the air of	during surgery can cause can	cer to spread.
	Yes, I agree	I am not sure	No, I disagree
9.	The amount of radiation a woman riding in an airplane.	gets from a mammogram is	less than what she gets from
	Yes, I agree	I am not sure	No, I disagree
10.	Mammograms can find breast lum	ps that are too small for doct	fors to find.
	Yes, I agree	I am not sure	No, I disagree
11.	More African American women g	et breast cancer than white w	romen.
	Yes, I agree	I am not sure	No, I disagree
12.	More African American women d	ie from breast cancer.	
	Yes, I agree	I am not sure	No, I disagree
13.	A 55 year-old woman has a higher	chance of getting breast can	cer than a 35 year-old woman.
	Yes, I agree	I am not sure	No, I disagree



THE WITNESS PROJECT® Training Post-Test

NA	ME:	DATE:	
	ase circle the response that best match your not sure. Your answers will let us know just		Answer every question, even if you
1.	The only way we have to treat breast cancer	is for a surgeon to remove a w	roman's breast.
	Yes, I agree	I am not sure	No, I disagree
2.	Mammograms are used to cure breast cance	r.	
	Yes, I agree	I am not sure	No, I disagree
3.	Bruising your breast can cause breast cance	r.	
	Yes, I agree	I am not sure	No, I disagree
4.	Women 40 years old or older should have any problems.	have a mammogram every	6 years, even if they don't
	Yes, I agree	I am not sure	No, I disagree
5.	If you check your breasts thoroughly a year.	every month you don't need	to get a mammogram once
	Yes, I agree	I am not sure	No, I disagree
6.	Breast cancer lumps are much more tr	reatable when found early.	
	Yes, I agree	I am not sure	No, I disagree

Master Key

_	. Mammograms are mainly good for women who feel a lump in their breast or have some other symptoms.		
	Yes, I agree	I am not sure	No, I disagree
8. Exposing b	oreast cancer to the air during surger	y can cause cancer to spread.	
	Yes, I agree	I am not sure	No, I disagree
9. The amoun	t of radiation a woman gets from a	mammogram is less than what she ge	ets from riding in an airplane.
	Yes, I agree	I am not sure	No, I disagree
10. Mammogra	ms can find breast lumps that are to	o small for doctors to find.	
	Yes, I agree	I am not sure	No, I disagree
11. More Africa	an American women get breast canc	er than white women.	
	Yes, I agree	I am not sure	No, I disagree
12. More Afric	an American women die from breas	t cancer.	
	Yes, I agree	I am not sure	No, I disagree
13. A 55 year-o	old woman has a higher chance of go	etting breast cancer than a 35 year-old	d woman.
	Yes, I agree	I am not sure	No, I disagree

Training Session Evaluation

Feedback from trainees in your WRM and LHA training sessions will be extremely valuable, as you are learning what works and what doesn't work.

The training evaluation form provided can be used in any type of learning setting. The form takes about 5 minutes to complete at the end of the program. Encourage trainees to give honest feedback and suggestions. Trainees should not put their names on the forms.

Results of the training evaluation should be given to the Project Coordinator who then forwards them to the Evaluation Coordinator.



THE WITNESS PROJECT®

Training Session Evaluation

PLEA	SE CHECK ONE:	Witness Role Model	☐ Lay Heal	th Advisor
TRAINING DATE: LOCATION:				
Please	circle the response th	at best represents your	opinion on the follo	wing statements.
1.	I had a clear understa	nding of the purpose fo	or the training before I	came.
	YES	SOMEWHAT	NO	NOT SURE
2.	The training was well	l organized.		
	YES	SOMEWHAT	NΟ	NOT SURE
3a.	The trainers were pre	pared.		
	YES	SOMEWHAT	NO	NOT SURE
3b.	The trainers knew wh	at they were talking ab	out.	
	YES	SOMEWHAT	NO	NOT SURE
3c.	The trainers said wha	t they had to say so I co	ould understand it.	
	YES	SOMEWHAT	NO	NOT SURE
3d.	The trainers used exam	mples that I could relate	e to my own experien	ces.
	YES	SOMEWHAT	NO	NOT SURE
4.	There was enough tim	ne to cover the informat	tion.	
	YES	SOMEWHAT	NO	NOT SURE
5a.	I felt comfortable ask	ing questions during the	e training session.	
	YES	SOMEWHAT	NO	NOT SURE
5b.	My questions were an	swered thoroughly and	confidently.	
	YES	SOMEWHAT	NO	NOT SURE
6.	The slides or visual ai	ds were helpful.		
	YES	SOMEWHAT	NO	NOT SURE
7.	I learned of resources	for information, screen	ning, and treatment.	
	YES	SOMEWHAT	NO	NOT SURE

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8a.	The hands-on act	ivities were helpful in ap	plying the informa	ation.
	YES	SOMEWHAT	NO	NOT SURE
8b.	The instructor(s) v	was helpful in coaching me	e through new skill	ls.
	YES	SOMEWHAT	NO	NOT SURE
8c.	I feel good about	my ability to apply the new	v skills and inform	nation in teaching others.
	YES	SOMEWHAT	NO	NOT SURE
Please	complete the for L	owing statements or answe	er the following qu	uestions.
Did an	y unexpected event	s (such as lighting, sound,	or room temperat	ure) positively or
negativ	ely affect your abi	lity to understand the infor	rmation?	
New in	formation I learned	l today was (please be spec	eific):	
The mo	ost helpful part of th	ne training was:		
In addit	tion to being a Witi	ness Project® team membe	er, ways in which	I can use today's training
include	_	J	, ,	, ,

Page 2 of 3 © 2000

WHAT CHA	WHAT CHANGES DO YOU RECOMMEND FOR FUTURE TRAININGS?		
LENGTH			
FORMAT			
INFORMATION			
LITERATURE			
OTHER			
Other comments or s	uggestions:		

Page 3 of 3

Trainer Evaluation

Everyone who shares training duties should complete a trainer's evaluation at the end of the program. Trainers assess the effectiveness of the curriculum, materials, and process, **not the trainers.** Information from this form provides a basis for refining your project as it grows.

Trainers should submit a completed form to the Training Coordinator, who may then make recommendations for technical assistance or changes in the training itself.



THE WITNESS PROJECT® Trainer Evaluation

NAME:			DATE:		
WRM	ORIENTATION	LHA TRA	AINING	COMBINED	
WRM	CONTINUING	EDUCATION	LHA CONTINUINO	G EDUCATION	
Please	circle the respon	ise that best represents	your agreement with	the following statements.	
1.	The session was	effective in meeting the	e purpose and objective	es of the training.	
	YES	SOMEWHAT	NO	NOT SURE	
2 .	The order of the	agenda was effective in	teaching new skills a	and information.	
	YES	SOMEWHAT	NO	NOT SURE	
3.	The manual and	handouts met the needs	of the participants.		
	YES	SOMEWHAT	NO	NOT SURE	
4.	The slides and/o	r videotapes were helpf	ul in reinforcing the c	urriculum.	
	YES	SOMEWHAT	NO	NOT SURE	
5.	As a trainer, I fe	lt confident in my know	ledge and skills.		
	YES	SOMEWHAT	NO	NOT SURE	
6.	I had adequate ti	me to prepare for my tra	aining responsibilities		
	YES	SOMEWHAT	NO	NOT SURE	

WHAT CHANGES WERE MADE FROM THE CURRICULUM? PLEASE EXPLAIN		
LENGTH		
FORMAT		
INFORMATION		
LITERATURE		
OTHER		
WHAT CHANG	ES DO YOU RECOMMEND FOR FUTURE TRAININGS?	
LENGTH		
FORMAT		
INFORMATION		
LITERATURE		
OTHER		
Other comments or sugge	estions:	

Team Member Evaluations

Evaluating your team members will help them develop confidence in their public speaking skills. You will want to approach the evaluation to find and build on strengths rather than deficits.

Because Witness Role Models are telling their stories, you will want to evaluate their demonstration of clear, sequential, and positive stories.

Unlike the WRMs, LHAs are responsible for communicating factual information and demonstrating accurate and proper performance of breast self-examination. Our experiences have found that new LHAs do not generally develop the required confidence and ability to present breast and cervical cancer education from an 8-hour training alone. Each LHA must observe 3 programs before presenting. Their first presentation is then observed and feedback is provided (as time permits) regarding factual information, responses to questions, and BSE demonstration skills. An annual performance evaluation should be provided as the LHA grows in her role as educator.

Program Checklist

It is **extremely** important that your team members are well prepared before each program. A checklist to organize materials assists your volunteers in communicating professional and committed images to the community.

Team members should always arrive at a program 20 - 30 minutes ahead of the audience, so that they have enough time to test the TV/VCR and arrange the display and handouts, and breast models.

You may find that the checklist may need to be revised as your Witness Project® develops and new resources are added. Projects are encouraged to use materials that are in accordance with current, national screening guidelines. Literature may be obtained from organization such as the Susan G. Komen Breast Cancer Foundation, the American Cancer Society, and the National Cancer Institute/Cancer Information Service.



The Witness Project® Program Checklist

<u>Supplies</u>		<u>Forms</u>	
	Breast Models (cleaned & powdered) MammaCare Brand (with simulated	☐ Sign-in Sheet	
	lumps) Transparent model	☐ Informed Consent Form	
	Opaque model HealthEdco (Ethnic Brand)	☐ Program Registration Form	
	Mini Geriatric	☐ Expense Reimbursement Form (for team members to complete and give or mail to Area Coordinator after	
	TV/VCR (if a unit is available)	Program)	
	Extension cord and adapter	☐ Witness Role Model (WRM) Application	
	Witness Project® videotape Your notes	☐ Lay Health Advisor (LHA) Application	
	Resources by county Telephone numbers BSE teaching booklet	HANDOUTS	
	Prompt Card		
	Bead Necklace (if available)	☐ The Witness Project® brochures	
	Pencils or pens	☐ Breast Self-examination (BSE) brochure	
	Clipboards	☐ BSE Shower Cards	
_	Your Witness Project® business cards	☐ Mammography brochure	
	carus	☐ Pap test & pelvic exam brochure	
		☐ Diet & nutrition information	
		☐ Preventive health services resources	•
		☐ Other	

Program Agenda

The Witness program agenda provides the **recommended** format for conducting a Witness program.

It may be helpful to laminate an agenda for team members to refer to during programs.



THE WITNESS PROJECT®

Program Agenda

Step 1	Greet participants and pass the Sign-in-sheet
Step 2	Introductions Prayer (Hymn and Scripture optional) Thanks for inviting us Witness Project® Overview - (Why we're here)
Step 3	Witness Project® Video - "If I Can Help Somebody"
Step 4	Stories - Witness tell their stories (2 to 3) 2-3 minutes (never more than 5 minutes) per story
Step 5	Present breast and cervical cancer information
Step 6	Resources [what are the available breast and cervical cancer resources in your area?]
Step 7	Distribute Program Registration Form and Informed Consent Form. [Explain that you would like to be able to follow-up and help participants get the services they need.]
Step 8	Teach breast self-examination (BSE)
Step 9	Invite questions
Step 10	Make closing remarks - Recruit WRMs and LHAs - Give contact information
Step 11	Prayer (Hymn optional)
Step 12	Practice BSE on ethnic breast models Gather up all materials and equipment Leave the room as you found it Don't leave anything behind
Step 13	Follow-up: Send thank-you note within one week of the program Complete reporting form and give it to your project coordinator Request any reimbursements Evaluate your program What went well? What might you do differently next time? Share information with other project members Pat yourself and your team members on the back

Continuing Education Log

As a Witness Project® grows, it is necessary to provide additional learning experiences for both WRMs and LHAs. Continuing education increases the confidence of team members in their abilities as peer educators and provides the social bonding necessary to maintain commitments and move the project forward.

In the Arkansas project, it is generally the responsibility of the Training Coordinator to work with the Steering Committee in determining educational needs and interest of the team members. Topics such as updated breast and cervical cancer screening and treatment practices support the content of the programs.

Team members who hold professional certifications or licenses (nurses, teachers, social workers and health educators) may be able to use your training toward those requirements.

Prompt Card

The Prompt Card includes cues on breast and cervical cancer and screenings for early detection (mammograms, Pap tests, clinical breast exams (CBEs), and breast self-examination (BSE). It is a good tool to help LHAs stay on topic while covering all pertinent points in educating people about breast and cervical cancer.

LHAs find that they develop their own presentation styles just as the WRMs do in relating their stories. It is often helpful for the LHA to refer to the Prompt Card at the end of her presentation, just to make sure that all points are covered.

The sample that follows can be reproduced. Like the program agenda, a laminated copy of the Prompt Card is very helpful.

Letter of Support Template

Most Witness Projects® often receive grant funding. In applying for funding, you may be asked to provide letters of support from organizations with whom you plan to work.

The following template may be used by any organization to draft a letter. The template provides a guide while allowing for individualization. Letters of support should be written on organizational letterhead.



THE WITNESS PROJECT® Letter of Support Template

Mattye J. Willis Deputy Director, The Witness Project® 4301 West Markham, Slot 629A Little Rock, AR 72205

Dear Ms. Willis:

Paragraph 1 establishes the support for the applicant. The opening sentence may be a statement of support for the applicant to implement a Witness Project® in the community. Additional sentences may reflect previous experiences or relationships the supporter has enjoyed with the applicant and other achievements of the applicant to which the supporter can attest.

Paragraph 2 supports the need for *The Witness Project*®. The opening sentence may contain a statement regarding the impact of breast and cervical cancer on the community as observed by the supporter. Additional sentences may attest to other needs such as a lack of culturally competent educational and outreach programs, the difficulty in accessing screening and treatment services, and the existence of other programs within the community or supporting organizations that will be enhanced by *The Witness Project*®

Paragraph 3 identifies how the supporter will work with *The Witness Project*®. The opening sentence may be a statement commitment. Additional sentences may specify how the supporting organization will work with *The Witness Project*®, such as provide meeting or office space, host 3 program that will educate 100 women, include *The Witness Project*® in an annual health fair, or provide van transportation to programs and screening services.

Paragraph 4 offers an appreciation for the opportunity to support the applicant in establishing a local Witness Project®. Be sure to provide a telephone number or e-mail address in the event additional information is needed.

Sincerely,

The Witness Project® © 2000 Revised 8/00

Appendix A – Form

Program Registration Form ✓

The *Program Registration Form* is an internal evaluation and navigational tool. This form solicits the basic information necessary to evaluate the effectiveness and outcomes from your Witness Project® education program. Unless you already have an evaluation system in place within your organization, you should use this form. In addition to evaluation, the purpose of this form is to facilitate access and utilization of services (mammography, clinical breast examinations, pelvic examinations, and Pap tests) to eligible women, and provide information. It will help you determine who needs to be navigated or assisted in obtaining these screening services. The information collected from this form will help you determine if your program is working and what changes are needed for better outcomes in serving program participants.

This form must be given to participants to complete at Witness Programs after Lay Health Advisors have cited facts and resources regarding breast and cervical cancer. The form reflects the age categories of women who are, and / or are not getting their mammograms, CBEs, Pap tests, pelvic exams and practicing BSE, and the types of assistance they require in getting these services.

Any time data is collected for evaluation purposes an approval from a Human Subjects review mechanism such as an Institutional Review Board (IRB) is required. The 2-page *Informed Consent Form* **must** be given with the *Program Registration Form*. Tell your participants they are being asked to complete an *Informed Consent Form* so that you will have their permission to contact them at a later date for whatever assistance they have requested to obtain the services they need. The Program Registration Form is a tool used to navigate women toward low or no cost breast and cervical cancer screening.

Appendix A – Forms

Some women may need assistance in scheduling screening, locating services, have questions about how services may be covered, need assistance with transportation, or want additional cancer literature.

If you don't already have a navigational system in place, you should develop some internal tracking tools for documenting follow-up with program participants.

Within one week after a program, the Navigator (team member or staff person) should contact each program participant who requested assistance with screening services on the Program Registration Form, and those who indicated they were not getting timely mammograms, CBEs, Pap tests, or pelvic exams. After you have provided for navigating those in need of services, use another blank copy of the Program Registration Form to contact the same participants within one month after the scheduled appointment to determine if mammograms, clinical breast exams, pelvic exams and/or Paps were received.

The **Program Registration Form** and the second page of the **Informed Consent Form** must be mailed to the attention of the evaluation coordinator at the National Witness Project® office in Little Rock, Arkansas. This must be done within one month of the program attended (if your project is covered by an IRB you do not have to mail us the Informed Consent Form). Mail the **Follow Up Sheet** when you have determined that the navigation process has been completed for a participant, e.g., mammogram or Pap test was done. To preserve confidentiality, black out the participant's name, address, and phone number on the Program Registration Form.

Forms should be mailed to the attention of *The Witness Project*® evaluation coordinator at 4301 West Markham, Slot 820 Little Rock, Arkansas 72205. If you have any questions, please call the evaluation coordinator at 501-661-9603 or 1-800-275-1183.



The Witness Project® **Program Registration Sheet**

Location_____

Na	me:							
Address:			County:					
City	7:		State:		Zip:	Phone:		
Plea	se check an ag	ge group	:Under 39	40-49	50-59 _	60-69	70-7980	
Ethi	nicity:A	African- <i>E</i>	American	_Caucasian	Hisp	anic	Other	
Plea	se check an ai	iswer to	each of the follo	wing question	ıs:			
1.	Have you exa	mined y	our own breasts (breast self-exa	mination or BS	E) in the past n	nonth?	
	Yes	No	If Yes, how oft	en?				
2.	Have you had	l a clinica	al breast examinat	tion (CBE) by	a doctor or nur	se in the past 12	2 months?	
	Yes	N o	If Yes, when?_		Month/Ye	ear		
3.	Have you had	a mamn	nogram (x-ray of	the breast) in t	he past 12 mon	ths?		
	Yes _	No	If Yes, when?_		Month/Ye	ear		
4.	Have you had	Have you had a pelvic examination in the past 12 months?						
	Yes	No	If Yes, when? _		Month/Ye	ear		
5.	Have you had a Pap test in the past 12 months?							
	Yes	N o	If Yes, when?_		Month/Ye	ear		
6.	•		Pap test and mam	•	•	how may The	Witness Project®	
H	Ielp me find Lo	ow or No	Cost Exams	Sched	ule a Mammogi	ram or Pap appo	ointment for me	
Help me with Transportation				Help r	Help me with Childcare			
	Cell me when a Unit is in my o		Mammography ty	I need	more Informati	on and Literatu	re	
P	lease help me v	with thes	e other problems:					
-		_	estions that you v ogram. They wil	_	_	se feel free to t	alk with one of the	
Signature:					Date:			
						© 2000		

Appendix B is divided into four sections after the introduction.

Section I include information on agencies and companies that you may want to contact. We have listed their telephone numbers, voice mail, e-mail, and fax numbers as available. Most we have already mentioned in the guide. They appear here in alphabetical order for easy reference.

Section II lists printed resources you may want to refer to. They include books, self-study guides, and journals. Section III lists electronic resources.

Section IV contains a comprehensive list of Breast and Cervical Cancer Early Detection Programs across the nation.

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Introduction: The Witness Project®

The witness Project® evolved from a breast cancer-screening project sponsored by the Arkansas Division of the American Cancer Society during National Breast Cancer Awareness month in 1988. In 1990, the project was developed under the direction of Deborah O. Erwin, PhD, assistant professor of surgery and associate director for education at Arkansas Cancer Research Center at the University of Arkansas for Medical Sciences, and Thea Spatz, EdD, CHES, associate professor of biology at the University of Arkansas at Little Rock. Since 1992, research on The Witness Project® as an educational intervention, has been supported by the Susan G. Komen Breast Cancer Foundation. In 1995, the National Cancer Institute funded expansion of the project into additional counties in Arkansas, and the Centers for Disease Control and Prevention (CDC) funded additional research through the Breast and Cervical Cancer Control Program at the Arkansas Department of Health. In 1997 The Witness Project® received a CDC grant award for Replication and Dissemination (R&D) of the project nationally. There are Witness Project® partners active in Arkansas; Wichita, Kansas; Bridgeport, Connecticut; Bloomington/Normal, Illinois; and Hattiesburg, Mississippi.

The initial goal of the four-year grant was to replicate *The Witness Project*® in at least six sites. Pilot sites chosen for 1998 were Oakland, California (Alameda County) and four sites within the state of Illinois, the home of a partner site. In Illinois the challenge was to take the state from a single Witness Project® program (Bloomington/Normal) in a private institution, to a network of Witness Project® programs beginning with three physical sites in Illinois other than Bloomington/Normal, a current partner. Pilot sites chosen within Illinois were Trinity Regional Health Systems' Parish Nurse Program in Rock Island, Illinois; DuPage A.M.E. Church in Lisle, Illinois; the Champaign-Urbana Public Health District, and YWCA TLC-Select, both in Champaign, Illinois. Since the pilot initiative began, the DuPage A.M.E Church and YWCA TLC-Select are no longer in the R&D program.

In addition to our partners and pilots, there are other Witness Project® partners. These are organizations that heard about *The Witness Project*® and purchased our training materials to implement the project in their areas. These sites do not receive any funding under our CDC grant, but are offered limited technical assistance. There are currently approximately 17 states in which there are Witness Project® partners.

Since its inception, *The Witness Project*® has been honored with a variety of awards. It received the National Honor Citation from the American Cancer Society in 1991 and the Achievement Award from the Wilowe Institute (Little Rock, Arkansas) in 1993.

Witness Role Models (WRMs) received the team HOPE award at the 5th Biennial Symposium on Minorities, the Medically Underserved & Cancer: Cultural Diversity, Public Policy, and Survivorship in 1995. The Arkansas Chapter of the International Association of Business Communicators (IABC) presented the 1995 Bronze Quill Award of Excellence to *The Witness Project*® for its video, "If I Can Help Somebody: Witnessing to Save Lives".

Drs. Spatz and Erwin received the Susan G. Komen Breast Cancer Foundation Community Service Award for Individuals in 1995, to recognize their work on *The Witness Project*® to reach medically underserved women in rural areas with vital breast and cervical cancer education and screening programs.

Section I: Agencies and Companies

African American Breast Cancer Alliance (AABCA)

Phone: 612-825-3675

The African American Breast Cancer Alliance (AABCA) was founded in Minneapolis, Minnesota by black women who have had breast cancer, as an advocacy group for women with breast cancer, their families, and the African American community. AABCA has formed coalitions with a variety of groups working toward increasing the survival rates of women affected by breast cancer, both regionally and nationally.

American Cancer Society, Inc. (ACS)

Phone: 800-ACS-2345

A nationwide community-based organization, the American Cancer Society is an excellent source for cancer statistics and printed educational materials. The ACS consists of a national society, 57 state (division) offices, and over 3,400 local offices (units). Major programs include Research, Public Education, Professional Education, Patient Services, and Public Issues/Government Relations. Their breast self-examination BSE video, "Special Touch", is multicultural; we think it's one of the best available.

Avon Breast Health Access Fund

Phone: 212-889-0606 Fax: 212-689-1213

This fund is a program of Avon's Breast Cancer Awareness Crusade, which is raising awareness and generating funding for breast cancer programs through the sale of items with pink ribbons. The fund was established in November 1993 to provide financial support to worthy community-based breast cancer programs that would have a direct and immediate impact on women's access to breast health education and early detection services. The fund will not support the cost of medical services themselves. Programs supported by the fund are 15 Organizations - National Alliance of Breast Cancer Organizations (NABCO) and volunteer support from local Avon representatives in their communities. There are two

funding cycles each year.

Breast Cancer Resource Committee

Phone: 202-463-8040 Fax: 202-463-8015

Black women find strength in a breast cancer support group of their own. Zora Brown, an African American breast cancer survivor, is founder and chairperson of this organization that provides information on African American breast cancer support groups. Call for more information.

Cancer Information Service (CIS)

Phone: 800-4-CANCER

The (CIS) is a nationwide network of 19 regional field offices supported by the National Cancer Institute. CIS offices are located at NCI-designated cancer centers and other health care institutions. Through its toll-free telephone service, the CIS provides accurate, up-to-date information on cancer to patients and their families, health professionals, and the general public, Calls are answered from 9:00 a.m. until 4:30 p.m. and are automatically routed to the office that serves your region. Through its outreach program, the CIS serves as a resource for state and regional organizations by providing printed materials and technical assistance to cancer education, media campaigns, and community programs. Your regional CIS outreach coordinator can connect you with groups who are already doing breast cancer education and detection in your area, provide you with appropriate speakers for your events, and send you materials to distribute during your project. FDAcertified mammography facilities may be located by calling the CIS. Since implementation of the Mammography Quality Standards Act of 1992, CIS has a current list of all facilities that have been certified by FDA as capable of providing quality mammograms.

EXCEL, Inc.

Phone: 800-822-4MAT

Fax: 708-382-4510

These are the folks who developed the 4MAT® System. Besides additional materials about the model, they can provide you with printed Learning Type

Measure and Hemispheric Mode Indicator self-assessment forms. A computerized (Macintosh) version of the Learning Type Measure is also available.

Health EdCo

Phone: 800-299-3366, ext. 295

Fax: 254-751-0221

This company is an excellent source for teaching materials and breast models. Call for a catalog. Most orders are filled within 48 hours and shipped UPS, which requires 7-10 working days. Several of their products are designed with a special place to display your name, logo, or other message.

Susan G. Komen Breast Cancer Foundation

Phone: 972-855-1600 Fax: 972-855-1605

Help Line: 800-I'M AWARE

The Susan G. Komen Breast Cancer Foundation was established in Dallas, Texas in 1982 by Nancy Brinker to honor the memory of her sister who died from breast cancer at the age of 36. The Foundation is a national organization with a network of volunteers working through local chapters and Race for the Cure® events in 32 states and the District of Columbia. The Foundation's mission is to eradicate breast cancer as a life-threatening disease by advancing research, education, screening, and treatment. Hundreds of thousands of women each year receive the life-saving message of early detection through Komen outreach efforts. The Komen Foundation is the nation's largest private funder of research dedicated solely to breast cancer. Through the Komen National Research Grant Program, grants and fellowships are awarded on an annual basis in both basic and clinical breast cancer research.

To date, research funded by the Foundation has significantly impacted diagnostic accuracy, treatment effectiveness, the role genetics play in the onset and development of breast cancer, and how and why this disease continues to develop.

The National Cancer Institute (NCI) recognizes the Komen Foundation's peer review process, which is used to select its grant recipients. The Foundation provides helpful information and resources to individuals with breast health or breast cancer concerns through its national toll-free Komen Help Line. Trained,

caring volunteers and breast cancer survivors answer questions and provide moral support. Callers can also use the help line for information about the Race for the Cure®, serving as a volunteer, setting up educational programs, or starting a Komen affiliate, from 9:00 a.m. to 4:30 p.m. (Central Standard Time). We recommend *The Race is Run One Step* at a Time by Nancy Brinker with Catherine McEvily Harris (1990, Simon and Schuster) for women who want to know more about breast cancer. It's a sensible guide to taking charge of a breast cancer diagnosis, and offering the reader a positive frame of mind. It is written from the point of view of a woman who has experienced and survived cancer, but lost her sister to the same disease. It includes lists of questions to ask your doctor, an action chart, photographs, and a comprehensive resource section. It uses down-to-earth language and is free of technical jargon.

Mammatech Corporation Phone: 800-626-2273

Fax: 352-375-6111

MammaCare® models and other BSE teaching materials are available from the Mammatech Corporation of Gainesville, Florida. The company invites inquiries regarding the design and costs of special programs for larger groups. Volume discounts are available.

National Alliance of Breast Cancer Organizations (NABCO)

Information Services: 212-719-0154

Phone: 212-889-0606 Fax: 212-689-1213

NABCO, a network of breast cancer organizations, was established in 1986 to provide information, assistance, and referral to anyone with questions about breast cancer. NABCO serves as a clearinghouse for information about breast cancer and voices the interests and concerns of breast cancer survivors and women at risk. NABCO has successfully collaborated with public and corporate partners on educational and medical programs, such as the October National Breast Cancer Awareness Month, an educational program established in 1984. NABCO also administers the Avon Breast Health Access Fund, a program of Avon's Breast Cancer Awareness Crusade to raise awareness and generate funding for breast cancer programs. Organizations and individuals may join this New York-based

information network. To reach the information services department, telephone this number and leave a message. Your call will be returned the next business day.

An extensive Breast Cancer Resource List, which may be photocopied and distributed for non-commercial use, is produced by NABCO annually. It is available for a minimal shipping charge. Call Information Services to order one or more copies.

National Black Leadership Initiative on Cancer (NBLIC)

Phone: 800-950-2045 Fax: 404-756-5298

Established by the National Cancer Advisory Board, the NBLIC is the National Cancer Institute's formal outreach initiative to establish a national system that will increase cancer prevention and control activities to reduce cancer mortality in the black population. The Initiative seeks to enlist concerned and active black leaders throughout the nation to help organize, implement, and support cancer prevention programs. NBLIC developed the ethnic "Get a Mammogram" pins and mammography and Pap tests brochures. The pins are no longer available but the brochures are available through the National Cancer Institute. For more information on NBLIC, call for the name and telephone number of your regional director.

National Breast and Cervical Cancer Early Detection Program (NBCCEDP) Centers for Disease Control & Prevention (CDC)

Phone: 770-488-4227 Fax: 770-488-4760

Congress recognized the lifesaving potential of early detection when it passed the Breast and Cervical Cancer Mortality Prevention Act in 1990, making national cancer screening programs a top public health priority. Funding to support local breast and cervical cancer screening efforts is provided through the Centers for Disease Control and Prevention to all state health departments. These programs are good resources provide screening and diagnostic services for eligible women and help with referrals for treatment.

National Cancer Institute (NCI)

Phone: 1-800-4-CANCER

NCI has free outreach materials for community breast and cervical cancer education programs. Some materials are written for specific audiences, including African Americans, the elderly, and people with limited-literacy skills. Brochures intended for readers with limited literacy have a reading level rating on the back cover. Federal Government publications are not subject to copyright restrictions, so photocopying is permitted. These can be ordered through the Cancer Information Service. Allow 4 to 6 weeks for the delivery of large orders.

National Coalition for Cancer Survivorship (NCCS)

Phone: 301-650-8868 Fax: 301-565-9670

The NCCS is a non-profit organization that promotes programs that empower survivors as informed consumers. NCCS links survivors to survivors and veterans to newcomers. NCCS provides information for living well after diagnosis; a voice in state and national forums for survivors' rights; regular and special publications; national assemblies and conferences; personal responses to inquiries; and a Speaker's bureau. Individual, organizational, and institutional memberships are available. A number of articles are available free of charge. Call for a complete list.

North Carolina Breast Cancer Screening Program (NC-BCSP) Jo Anne L. Earp, ScD, Principal Investigator

Phone: 919-966-7971,72

Fax: 919-966-4249

NC-BCSP is a consortium of state and local public health agencies and universities. A research team at the University of North Carolina's Lineberger Comprehensive Cancer Center in Chapel Hill, South Carolina Hill directs this consortium. They seek to increase breast cancer screening rates among African American women ages 50 and older and ultimately eliminate the racial gap in breast cancer mortality which studies show exists. Three complementary interventions are used: InReach, OutReach, and Access:

• InReach consists of activities to assist local health departments and rural

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Community health centers in restructuring clinic procedures and offering provider education on breast cancer screening.

- OutReach is aimed at empowering the women themselves as well as the communities in which they live through the development of a Lay Health Advisor network.
- Access is a set of activities designed to overcome structural barriers that prevent low-income, rural women from getting mammograms.

Office of Minority Health Resource Center (OMH-RC)

Phone: 800-444-6472 Fax: 301-589-0884

The Office of Minority Health, U. S. Department of Health and Human Services, and Public Health Service established OMH-RC in October 1987, as a national resource for minority health information. The resource center maintains an extensive database of minority health organizations, community programs, and publications. In addition to a variety of free publications, the staff has prepared a resource guide, Breast Cancer and Minorities. OMH-RC can put you in touch with experts who specialize in cancer and can serve on committees, speak at workshops, and provide technical assistance.

Save Our Sisters Program Eugenia Eng, DrPH, Principal Investigator

Phone: 919-966-3909 Fax: 919-966-2921

The Save Our Sisters (SOS) program, an NCI-funded project, began in 1990. Since that time, over 90 natural helpers have been trained to become lay health advisors. SOS advisors raise awareness about breast cancer and the need for screening through one-on-one counseling and group presentations. They help other community women overcome barriers to mammography screening, including fear, cost, and transportation. The lay health advisor model used by the SOS program has been adopted by the North Carolina Breast Cancer Screening Program (NC-BCSP), forming the basis for NC-BCSP's outreach intervention. This is an excellent resource for more information on lay health advisor training.

Sisters' Network

Phone: 713-781-0255

Sisters' Network is the first national African American breast cancer survivors support group. The organization was established in 1994 to unite survivors, the community, and health professionals for the sole purpose of fighting breast cancer. Breast cancer survivors, who are committed to establishing breast health services in their community, organize these chapters. Donations and funds raised by chapters provide education, resources, and referral opportunities for women.

Y-Me National Breast Cancer Organization

Phone (Hotline): 800-221-2141

Fax: 312-294-8598

The Y-ME hotline, staffed exclusively by breast cancer survivors, offers presurgical counseling, information on treatment options and support to those facing a diagnosis of breast cancer.

This Chicago-based organization also runs a men's hotline for those who have experienced a partner's (or their own) cancer diagnosis. It is answered by trained volunteers and breast cancer survivors on weekdays from 9:00 a.m. to 5:00 p.m. (CST).

Stephens YWCA EncorePlus®

Hot-line 1-888-663-3914

Web-site: http://www.ywcaencore.org

Fax: 501-663-0204

This local has reached about 10,000 women through educational outreach, and has enrolled 4,000 women as members whom it tracks and communicates with about their annual screenings. It exists to reduce the mortality rate of breast and cervical cancer in Arkansas by increasing the number of women who regularly obtain annual screening exams for early detection. The primary population is medically underserved women of all ages in the state of Arkansas. The program educates women about the need for early detection and helps them overcome barriers to getting their screening exams.

Section II: Printed Resources

Breast Cancer/Black Woman Van Slyke & Bray 4152-C Carmichael Road Montgomery, AL 36106

This primer to help the African American woman survive breast cancer by Edwin T. Johnson, MD, was published in 1993. This book was written to raise awareness that breast cancer can be cured. Early detection is emphasized. Options now available in the care of breast cancer are presented to encourage black women to participate in treatment decisions. (Hardcover; 170 pages, 52 pictures, 25 in full color. Cost: about \$20 plus shipping and handling.)

The Breast Cancer Companion

Kathy LaTour, a professional journalist, was diagnosed with breast cancer in 1986 at the age of 37. In 1993, she published The Breast Cancer Companion, a sensitive and authoritative book with information on every decision a breast cancer patient will face, from diagnosis through the healing process. It was written with the expert counsel of surgeons, psychologists, and other breast cancer specialists and is well organized. It includes narratives from more than 75 survivors and the men who loved and suffered with them. The Breast Cancer Companion, published by William Morrow and Company, is available in bookstores nationwide. Ms. LaTour lives in Dallas and teaches writing at Southern Methodist University.

Celebrating Life: African American Women Speak Out About Breast Cancer

USFI Publishing Phone: 800-422-2898

This book, which features the experiences of African American breast cancer survivors, was published in 1995. Author Sylvia Dunnavant demonstrates lessons in courage and initiative by presenting the experiences of real women (and one man) from all walks of life. They speak of denial, depression, anger, and pain, as well as of God, prayer, trust, and celebrating life. Two of our Witness Project® role models are included — Dorothy Ballard of Little Rock and Alice White of

Helena.

Developing Intervention Strategies for Breast Cancer Screening: A Self-Study **Guide for Program Planners**

Phone: 770-488-4751 (CDC)

This self-paced program, created in 1994 by the AMC Cancer Research Center (Denver) in collaboration with the Centers for Disease Control and Prevention, offers the health educator, or program planner the opportunity to enhance knowledge, and skills in developing community-based strategies for reaching women with breast and cervical cancer screening programs. This free guide is divided into five sections; completion time is approximately 3 hours.

The Witness Project® Phone: 800-275-1183 Fax: 501-686-6479

The following are articles with more information on *The Witness Project*®.

Spatz TS: Improving breast self-examination training by using the 4MAT instructional model. Journal of Cancer Education, 6:179-183, 1991.

Erwin DO, Spatz TS, Turturro CL: Development of a role model intervention to increase early detection of breast cancer in African American women, Journal of Cancer Education, 7:311-319, 1992.

Erwin DO, Deloney LA, Dai H, Erkman L: The Role of the cancer registry in building outreach programs: The Witness Project® Example, Journal of Registry Management, 23(2), 1996.

Erwin DO, Spatz TS, Stotts RC, Hollenberg JA, Deloney LA. Increasing mammography and BSE using *The Witness Project®* model: A paradigm for cancer education in special populations, Journal of Cancer Education, in review.

Section III: Electronic Resources

The Witness Project® Phone: 800-767-3824 Fax: 501-686-6479

Listserv: Witness-L@Life.uams.edu

The Witness Project® provides for a discussion group on its Internet listserv for Witness Project® Partners, pilots, affiliates, and anyone interested in starting a Witness Project® program. The discussion group, created by *The Witness Project*® staff at the University of Arkansas for Medical Sciences, through a grant from the CDC, is open to anyone who would like to discuss issues concerning *The Witness Project*®.

The discussion group serves as a forum for:

- Sharing ideas concerning long-range and day-today operations of *The Witness Project*®
- Discussing problems, opportunities, technical assistance and methods for cancer education outreach for African American women
- Posting information regarding standards, program suggestions, funding opportunities, and technical assistance
- Announcing national, regional, and Witness Project® partner meetings
- Discussing issues regarding recruitment, training, evaluation, impact measures, quality assurance, implementation, implementation package materials, and educational materials
- Other relevant issues to *The Witness Project*® locally and nationally

The Witness Project® Phone: 800-275-1183 Fax: 501-661-9603

Web-site: Witnessproject.uams.edu

Please visit our web-site. Here you will find an overview of *The Witness Project*® including our activities, research, history and design, as well as publications and abstracts. If you are interested in setting up a Witness Project®, information is here to tell you where to begin, including materials that are available for purchase. Profiles of some of our Witness Project® partners may be seen here. There are also links to other cancer education and outreach sites.

Your local media can help you increase awareness about your Witness Project®, as well as reach women in your community who need information and education about cancer and available services. The press is a powerful tool. You can use it to help deliver your message.

Why Publicity?

By creating publicity, you win media coverage for your project's newsworthy information or activities. Publicity tools include press releases, photos, feature articles (case histories, how-to stories), interviews, press conferences, and ongoing editor contact. Opportunities for publicity will depend on your project's activities, but might include an announcement of your advisory board appointments, an anniversary celebration, or coverage of your annual meeting.

A designated time to promote minority awareness of cancer issues is National Minority Cancer **Awareness Week** observed in April each year. The month of October is devoted to **Breast** Cancer Awareness. These present excellent opportunities to promote your project. A variety of generic publicity materials are available through the Cancer Information Service (CIS).

One word of caution: Don't make the common mistake of equating **your** interests with the media's. Realize they simply cannot cover everything you ask them to cover. Don't take their rejection personally.

Brochure

When we first needed to increase awareness about the Witness Project® in Arkansas, we worked with H. K. Stewart, a local writer/graphic designer. He recommended a brochure for this purpose, and it's been an effective tool for our project.

The following advice is his:

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> "A brochure is like a business card, but with a lot more information. You can mail it, or you can give it away whenever you meet with someone to talk about the project. If you forget to mention something when talking about the project, the brochure serves as your back-up to assure the information gets to the audience."

Recipients can refer to a brochure at a later date and follow up if they choose to, or they can use it to share information about the project with others (tell-a-friend).

A carefully designed brochure conveys the key facts about your project as well as its emotional aspect. It can explain your project, its goals, history, and benefits. You can also include names and addresses of contact people and a list of sponsors.

Your audience, your message, and the method of delivering the message to the audience must be considered when designing a brochure. Ours is a singlefold piece that fits in a standard business envelope. Photographs break up the copy and create visual interest, and color provides emphasis. It was written with the audience in mind, to convey the message in a manner neither insulting nor intimidating. The cover was designed to stimulate curiosity — to give the reader a reason to pick it up and read it.

If you want to create a brochure for your project, you can do-it-yourself on your copier or get professional help, depending on your budget. A sample brochure can be found on pages 10 and 11.

Local quick copy facilities are a relatively economical resource. You can take them your ideas and words; they will provide some design and production expertise at a minimal cost. One warning about brochures: The more jobs you expect your brochure to do, the less effective it

will be at doing any of them. For this reason, our brochure is not a tool for inviting someone to attend a witness program, for recruiting volunteers, or for soliciting contributions.

Photographic Exhibit

One of our most effective publicity tools is a series of black and white photographs of witness role models which were produced by Andrew Kilgore, a local photographer/artist who was interested in creating a visual representation of the Witness Project

When these framed photographs have been displayed with a brief description of the project the exhibit has generated interest in the program.

This exhibit also helps with recruitment at various community and church sites to stimulate cancer survivors and other local women to become involved in this outreach program.

Local Media List

Using your telephone book, develop a local media list of radio and television stations and weekly and daily newspapers, magazines, shoppers' news, and other publications in your area. Include media outlets that focus on ethnic audiences.

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Telephone each outlet to get the name of a contact person — the specific reporter, editor or news director who handles the subject matter — and the correct mailing address. Update this list every year.

Press Release

You may be able to generate publicity by simply sending a press release to your local media, especially in rural areas. A follow-up telephone call will help convince them the story is worth covering.

Type your release on appropriate letterhead or plain white paper. Use 8½" by 11" paper, and double-space.

Include a contact name and telephone number in case the reporter needs additional information, the release time and date for the news story, and a short headline. Using the 5 W's and H — who, what, when, where, why, and how — write a 1-page to 3-page release. Just tell your story, putting the most important facts first. You can learn a lot about news release writing by simply reading the newspapers in your area.

Imitate their style and you'll probably be fairly well on target. A sample press release can be found on page 13.

Whenever possible, include a 4" by 6" or 5" by 7", black and white or color photo. Action photos are preferred. Type a photo caption on paper and tape it to the back of the photo (or on a computer label and stick it on).

Don't write on the back of a photo. The caption should identify who is in the photo from left to right by full

The Witness Project® © 2000 Revised 3/2004 name, title, and organization. Identify the date and place the photo was taken. If you want the photo returned, say SO.

To increase your chances for coverage, address the release to a specific contact person. Otherwise, simply send the release to *News Editor*. You may want to attach a brief personal note with each release, especially if you know the contact.

Send press releases to all the contacts you make during the life of your project. If they don't run your news release, they may do a story on your program at a later date, especially when you have success stories and program statistics to share.

Press Conference

A press conference gives you the opportunity to highlight some aspect of your Witness Project®. It also gives you a platform to discuss your ongoing work and to highlight previous successes.

To determine if you are likely to have a good turnout for a press conference, consider...

- the size of your community
- the number of available local media outlets
- your lead time and who can help plan the event
- the uniqueness of your program
- who will speak at the press conference

Invite local or state officials to participate; having the mayor or a celebrity there greatly increases your chance for coverage. And the official's staff will often help plan

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the event. They have strong media contacts and they will want to assure their boss makes a good appearance. Invite a breast cancer survivor to speak, preferably someone affiliated with the project.

Review key points with your speakers ahead of time to ensure everyone is communicating the same message.

Remind them to avoid jargon or technical language, and encourage them to...

SAY . . . Finding cancer early NOT . . . Prevention, Protection

SAY . . . Successful treatment NOT . . . Cure SAY . . . Women diagnosed with cancer SAY . . . Breast cancer survivor NOT . . . Victim

Select an appropriate place that is large enough to accommodate the number of people you expect, with convenient access and parking. Create some visual interest or a photo opportunity for the media.

Schedule your conference between 11 am and 2 p.m. Many reporters don't start work before 10 am. If you schedule your conference too early you risk missing them.

And you don't want to schedule too late, since most reporters are under deadline-pressure in the afternoon. Deliver your message in 30 minutes or less. Use no more than 5 speakers, no more than 10 minutes each.

Invite the media a week in advance. Use a **Media Advisory** that includes who, what, where, when, and why of your event [see page C-16]. Telephone each media outlet to make sure they received your advisory. Ask if they are interested in doing a story.

Offer to answer any questions they have. Emphasize the importance of the program to local area African

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American women. Invite them to an event you have planned so they can see the program in action. If a particular reporter or editor is not interested, ask if someone else on staff might want to cover the story. If they ran a similar piece recently, they probably won't cover your story. Offer to serve as a source of information if they decide to cover the issue of breast cancer at a later date.

Press Kit

If you decide to hold a press conference, you'll need to prepare a press kit to hand out to reporters. Use a pocket folder for your press kit materials, and organize them with the most important materials in front.

Include a copy of the media advisory, your press release, a fact sheet, a backgrounder, a list of contributors/supporters, your brochure, and previous stories. You want to make the reporter's job easier by providing plenty of information about your project.

Use the Backgrounder contained in this section [p. 17] or write one specific to your project. Develop a fact sheet [see sample, page 20] including information on the project and on the importance of early detection.

Compile a list of supporters of your project [see sample on page 22].

Reporters may want to interview someone involved in your program or a breast or cervical cancer survivor. Have someone who is comfortable being interviewed talk with the reporters.

Be prepared to answer questions about any current controversies related to breast or cervical cancer. If

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you're not confident that you can answer, have another source to refer reporters to.

Be sure to send a press kit to any local media who did not attend the press conference a day or two after the event. Include a photo from the event.

Public Service Announcements

Public Service Announcements (PSAs) are usually 30 seconds or 1 minute in length. They can be excellent tools for promoting your project and message through broadcast media. Make a list of PSA Directors in your area (like you did media contacts), including the ABC, CBS, NBC, and FOX affiliate stations, any independent stations, and local radio stations, and the appropriate mailing addresses.

If you are able to determine which radio stations African American women in your community listen to, target those stations.

Send a copy of the PSA, with an introductory letter, to the contacts. Explain that you would like the station to run the PSA at no charge. Follow up with a phone call to remind them of your request.

If someone on your advisory board regularly pays for advertising with the station, you may have better negotiating power. If a number of individuals make a similar request, your chances for a positive response increase.

PSAs can also be placed in print media. Contact the retail-advertising manager of your local publications for

> these. They may give you a free ad once in a while. And sometimes businesses that advertise regularly will devote a small portion of their space for a drop-in ad — a little message that is included in a bigger ad — like, *Helen's* Beauty Salon supports The Witness Project®.

The Cancer Information Service can provide you with PSAs developed for National Minority Cancer Awareness Week. Eventually, however, you will probably want to develop your own. That task is beyond the scope of this manual, but you will probably make contact with a professional who will help with this through your advisory board or your early publicity efforts.

Video

Our 13-minute descriptive video, *If I Can Help* **Somebody: Witnessing to Save Lives,** is a good publicity tool. The video demonstrates the nature of the Witness Project® as a cancer education outreach program for African American women, the nature of the women who serve as Witness Role Models, and Lay Health Advisors, and what the program is trying to accomplish. It speaks for the team members, and is especially effective for presentations to civic organizations and other community groups. With the video, any team member can effectively present the project. Copies are available from the Witness Project® in Arkansas (visit our web site at witnessproject.uams.edu).

Sample Brochure

Back Cover Front Cover

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WITNESS SUCCESS

THE WITNESS PROJECT® is a program that can save lives. If you want to know what you can do-or if you want to have this program in your church or organization, please let us hear from you:

1-800-275-1183

Through their support of the ARKANSAS WITNFSS PROJECT®, the following organizations are largely responsible for its success.

- · American Cancer Society, Arkansas Division
- Arkansas Cancer Research Center at the University of Arkansas for Medical Sciences
- Arkansas Breast and Cervical Cancer Control Program at the Arkansas Department of Health
- · Avon Breast Health Access Fund
- · Central Arkansas Radiation Therapy Institute
- Delta Health Education Center
- National Black Leadership Initiative on Cancer
- · National Cancer Institute
- · Susan G. Komen Breast Cancer Foundation
- Health Education Program at the University of Arkansas at Little Rock

Current national expansion of the WITNESS PROJECT® is supported by:

• The Centers for Disease Control and Prevention

We are interested in offering this program to more communities, but we need more volunteer "witnesses." A training program is available for women who want to help us, as is a videotape"If I Can Help Somebody-Witnessing to Save Lives." To learn more, please call or write to:

Arkansas Cancer Research Center 4301 West Markham, Slot 629-A Little Rock, Arkansas 72205

THE WITNESS PROJECT®

WITNESSES



IN CHURCH, PEOPLE WITNESS TO SAVE SOULS.

AT THE WITNESS PROJECT THEY WITNESS

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Sample Brochure Inside Panels

WITNESSES FOR LIFE

BODY AND SOUL

THE WITNESS PROJECT® is a health program for African-American women in churches and community centers. It features a group of



AfricanAmerican
women who
each "witness" about
their triumph over
breast or
cervical cancer.
Together,

they preach the good news that cancer doesn't have to be an automatic death sentence. The key is to catch it early and get it treated.



The project offers more than just hope, though. It also teaches women some simple things they can do in their own lives to protect themselves against breast and cervical cancer. Things like breast self-examination.



Trained health instructors at each program use special breast models to show the audience how they can check themselves for signs of breast cancer. The audience members then get a chance to practice what they've learned by searching for lumps in the models.

In addition, the instructors answer questions about things like Pap tests (a test to find cervical cancer) and mammograms (a special kind of x-ray to look for breast cancer). Women will have a chance to find out where in their community they can have these tests done at low (or even in some cases no) cost.

Photos by Andrew Kilgore

Sample Press Release

[ON LETTERHEAD]

Media Contact:

Ms. Charlie Stayton **UAMS Medical Center** (501) 686-8801 or (501)-603-5203

WITNESS PROJECT® ANNOUNCES "AMEN" REVIVAL

Annual Meeting for Education and Networking

LITTLE ROCK — African American Arkansas women, especially breast cancer or cervical cancer survivors, are invited to attend the "AMEN Revival," the annual meeting for the Witness Project®.

The all-day meeting will be held, beginning at 8:30 a.m., on April 13 at the Arkansas Cancer Research Center, on the campus of the University of Arkansas for Medical Sciences, 4301 W. Markham. The agenda for the day includes entertainment by the Philander Smith College Vocal Ensemble; a keynote address by Lois Smith Williams (20-year breast cancer survivor from Dallas); a session on survivorship issues presented by Dr. Stephanie Simonton-Atchley - Director of the Behavioral Medicine program at UAMS; and a special awards and recognition luncheon honoring Witness Project® volunteers.

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There is no charge to attend the event, but registration is required. For more information or to register, call Marilynn E. Fulton at (501)-686-8801 or 1-800-767-3824.

Special workshop sessions during the AMEN Revival will include a discussion of the Witness Project® by its co-founders, Dr. Deborah O. Erwin of the Arkansas Cancer Research Center and Dr. Thea S. Spatz of the University of Arkansas at Little Rock. There will also be a discussion regarding services and resources available to cancer patients; a presentation on the importance of nutrition by Patricia Bryant, Chief of Dietetic Services at the Veterans Affairs (VA) Medical Center, and instructor at UAMS. Workshops on the treatment of breast and cervical cancer will also be presented by Dr. Groesbeck P. Parham, director of gynecological oncology at UAMS and by Dr. James E. Hagans III, a Little Rock surgeon.

The Witness Project® is a culturally competent, community-based cancer education program through which a team of African American cancer survivors and other African American women who are not cancer survivors, but want to help spread the word, increase awareness, knowledge, screening, and early detection behaviors among rural and lower income women in the Arkansas Mississippi River Delta region.

Witness Role Models help educate other women about the importance of early detection by witnessing, or talking about their cancer experiences to groups of women in churches and community centers and other sites in rural central and eastern Arkansas.

Non-cancer survivors, called Lay Health Advisors, teach breast selfexamination, provide information on mammograms, clinical breast exams, pelvic examinations and Pap tests, and cite available resources in the community that provide these early detection preventive health services.

Sponsored by the Arkansas Affiliate of the Susan G. Komen Breast Cancer Foundation, this meeting was made possible by proceeds from their *Race for the Cure*® event.

The Witness Project® is an outreach program of the Arkansas Cancer Research Center that is currently funded by the National Cancer Institute, and the Susan G. Komen Breast Cancer Foundation. National expansion of the Witness Project is being made possible by the Centers for Disease Control and Prevention (CDC)



Sample Media Advisory

[ON LETTERHEAD]

Contact: Mattye Willis, Deputy Director

> Arkansas Cancer Research Center 4301 West Markham, Slot 629-A

Little Rock, AR 72205

501-686-8801

MEDIA ADVISORY

WOMEN LEGISLATORS JOIN FORCES WITH CANCER CENTER, HEALTH DEPARTMENT IN FIGHT AGAINST BREAST CANCER

Members of the Arkansas Women's Legislative Caucus will WHAT: join officials from the Arkansas Cancer Research Center and the Arkansas Department of Health to show their concern over the number of lives lost each year to breast cancer and to voice

their support for early screening and detection.

October is National Breast Cancer Awareness month.

Wednesday, October 26, 1994 at 2:00 p.m. WHEN:

WHERE: Arkansas Cancer Research Center (ACRC)

University of Arkansas for Medical Sciences (UAMS)

4301 West Markham, Little Rock 72205

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Media Advisory — page 2

WHO: Fay Bozeman, Executive Director, AR State Health Department

Harry P. Ward, MD, Chancellor of UAMS

Bart Barlogie, MD, Director of ACRC

Rep. Josetta Wilkins of Pine Bluff, a breast cancer survivor

Rep. Carolyn Pollan of Ft. Smith

Reps. Myra Jones and Irma Hunter Brown, both of LR, AR

Rep. Dee Bennett of North Little Rock

Rep. Marion Owens of Warren

Rep. Judy Smith of Camden

WHY: For the year 2000, the number of new cases of breast cancer are estimated at 182,800 nationally and 1,900 for Arkansas; breast cancer deaths are estimated at 4 1,200 nationally and 400 for Arkansas.

Mammography can prevent fully a third of deaths from breast cancer, yet only 42% of women over the age of 50 have an annual mammogram in Arkansas.

Members of the caucus will accompany one of their members to receive a mammogram in an effort to help dispel fears about the procedure for other women.



Sample Backgrounder

THE WITNESS PROJECT®

The Witness Project® is a culturally competent community-based cancer education program through which a team of African American cancer survivors, and other African American women (Lay Health Advisors), increase awareness, knowledge, screening, and early detection behaviors among rural and lower income women in the Arkansas Mississippi River Delta region. "In church, people witness to save souls. At the Witness Project®, they witness to save lives."

As a health education program, *The Witness Project*® is designed to meet the specific cultural, educational, knowledge, and learning style levels of rural, medically underserved African American women. Program sessions are led by a team of African American breast and cervical cancer survivors who teach other women the importance of early detection by "witnessing", or talking about their cancer experiences.

Witness Project® programs are presented in churches, community centers and other settings. During a program session, these Witness Role Models share their experiences with cancer, stressing the importance of cancer screening and answering questions about their personal experiences, fears, and concerns. Witnessing is done by 2 to 5 role models to audiences of up to 25 participants. At least 2 witnesses participate in each session to avoid the appearance of a token survivor. The session addresses the fears and beliefs many women hold about cancer, demonstrates that the diagnosis of cancer is neither a death sentence nor a punishment, and provides participants with accurate, personal information about cancer, early detection, and treatment methods. Lay Health Advisors use ethnic breast models to teach Breast self-examination at each program.

The Witness Project® grew out of a 1988 breast cancer-screening project sponsored by the Arkansas Division of the American Cancer Society during National Breast Cancer Awareness month.

Backgrounder — page 2

This was the American Cancer Society's first big push to raise awareness of the disease in Arkansas.

In 1990, the Witness Project® was developed under the direction of Thea Spatz, Ed.D., CHES, and Deborah 0. Erwin, Ph.D. Spatz, a certified health education specialist, is coordinator of the health education program at the University of Arkansas at Little Rock (UALR). Erwin, a medical anthropologist, is Assistant Professor in the Division of Surgical Oncology and Associate Director for Education for the Arkansas Cancer Research Center at the University of Arkansas for Medical Sciences (UAMS).

The Witness Project® was the first program in Arkansas for socioeconomically and disadvantaged women through African American churches. In the early stages of the Witness Project®, work was funded through a Cooperative Research Grant from UALR, a one-year Demonstration Project Grant from the American Cancer Society, Arkansas Division, and a Title XX Grant from the Arkansas Department of Health in 199 1. Since 1992, research of the Witness Project® as an educational intervention, has been supported by the Susan G. Komen Breast Cancer Foundation.

Data from the pilot project was published in the *Journal of Cancer* Education in 1992. Since 1992, research of the Witness Project®, has been supported by the Susan G. Komen Breast Cancer Foundation of Dallas, Texas. The research includes 461 women from the Arkansas Delta region. Women in intervention and control groups are interviewed before a witness session and 6-months later to assess their beliefs, attitudes, knowledge, and practices related to breast and cervical cancer screening. Women who participate in Witness programs demonstrate significant changes.

Women who have been difficult to reach through traditional health education methods are attending witness programs.

The program, which is culturally sensitive, attracts the interest of low income, less educated, rural African American women. Some 45% of the program participants have less than a 12th grade education; 52% reported annual incomes under \$10,000.

When asked, have you ever talked with other women about breast cancer? the majority (54%) reported No. Fifty-five (55%) percent of the women have never had a mammogram, and only 30% reported their doctor had ever recommended one. Thirty percent (30%) of the women reported they never had a breast examination by a physician.

In 1994, the Avon Breast Health Access Fund supported development of a brief professionally produced video, *If I Can Help Somebody: Witnessing to Save Lives*, which features the role models who founded the project. From a pool of 340 applicants, the Witness Project® was one of the first 18 programs to receive funding from this new grant, representing the largest corporate contribution ever to breast cancer organizations on the local level.

The Witness Project® received the National Honor Citation from the American Cancer Society in 1991. The project received the Achievement Award from the Wilowe Institute of Little Rock, Arkansas in 1993. Witnesses received the team **HOPE** award at the 5th Biennial Symposium on Minorities, the Medically Underserved & Cancer: Cultural Diversity, Public Policy and Survivorship in 1995.

Sample Fact Sheet

WHAT AFRICAN-AMERICAN WOMEN NEED TO KNOW ABOUT CANCER

- **Breast** cancer is the **most common** form of cancer in women in the United States. It occurs rarely in men. Its cause and the means for its cure are undiscovered. More than 1.6 million breast cancer survivors are alive today.
- Every woman is at risk for breast cancer. The risk of developing breast cancer increases as she gets older, rising sharply after age 40. If she has a mother, sister, or daughter who had breast cancer, her risk is greater.
- From 1989 to 1993, breast cancer death rates for white women declined 6%. There has not been a similar decline for African American Women (Dr, Samuel Broder, Director of the National Cancer Institute, January 10, 1995)
- African American women with breast cancer are more than twice as likely to die from the disease than white Americans, primarily because they are diagnosed at more advanced stages of disease.

 (Journal of the national Cancer Institute, June 17, 1992)
- Only 66% of African American women survive their breast cancer
 5 years, compared to 80% of white women. (Ca-A Cancer Journal for Clinicians, Vol. 45, No. 1 January/February 1995)
- Finding breast cancer early saves lives. More than 90% of women who found breast cancer at its earliest stages are alive and well.

Fact Sheet - Page 2

Having a mammogram is a fast, safe, easy way to find breast cancer early. Medicare, Medicaid, and some private insurance companies cover screening mammograms.

- When breast cancer is detected early, women have more choices in treatment. Lumpectomy (removal of the lump only) followed by radiation therapy is an effective way to treat early stage cancer without removing the breast.
- African American women are twice as likely to develop cervical cancer and nearly three times as likely to die from it than other women. (National Cancer Institute, December 1992)

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Sample Supporters and Contributors List

THE WITNESS PROJECT®

The Witness Project® has received support from the following organizations:

- American Cancer Society, Mid-South Division, Inc.
- Arkansas Cancer Research Center at the University of Arkansas for Medical Sciences
- Avon Breast Health Access Fund
- Centers for Disease Control & Prevention through the Arkansas Breast and Cervical Cancer Control Program at the Arkansas Department of Health
- Central Arkansas Radiation Therapy Institute
- Delta Health Education Center
- National Black Leadership Initiative on Cancer
- National Cancer Institute
- Susan G. Komen Breast Cancer Foundation, Arkansas Affiliate
- Susan G. Komen Breast Cancer Foundation, Dallas, Texas
- University of Arkansas at Little Rock

Sample PSA Request Letter

[date] [name] Public Service Announcement Director [station name] [mailing address]

Dear [Mr. or Mrs.] [last name]:

The enclosed Public Service Announcement (PSA) was developed for use with the Witness Project®, which is being sponsored by the [sponsoring organization] in our community. Its purpose is to help educate African American women about the importance of early detection of breast and cervical cancer. By broadcasting this PSA on [station name], you will help spread our message.

African American women with breast cancer are more than twice as likely to die from the disease than white Americans, primarily because they are diagnosed at more advanced stages of disease. African American women are twice as likely to develop cervical cancer and nearly three times as likely to die from it. Through the Witness Project®, a number of individuals and groups in our community are working to save these lives [add brief information about your local activities or advisory board members that would create interest].

Thank you for lending your support to our project.

Sincerely,

[your name] [your organization] [advisory board member's name] [member's organization]

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Sample Photo Release Form

ragree to allow my photograph to be us	sed in cancer educational material.
	Date

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This section contains administrative information that will be of assistance to you as you determine staffing and the budget for your project. Included in this section are key job descriptions, timelines and budget examples.

Use the job descriptions according to the size / scope of your project, and the method of evaluation for the project. In addition to your recruited team members (WRMs and LHAs), at a minimum, your project must have a project director, outreach coordinator, and a navigator to follow up with program participants.

Examples of timelines may assist you in determining where you expect your program to be within a specific time.

Budget examples are shown to help you manage the financial requirements of your program. Specific examples of budgets for Witness programs are labeled shoestring (small), moderate and regional (statewide).

The Witness Project®

Project Director

Position Purpose:

Directs the overall operations of the project.

Duties and Responsibilities:

A good project director is one who possesses excellent organizational and communication skills. After all, this person is responsible for overseeing the implementation of project activities, coordination with other agencies, development of materials, provision of in-service and training, meeting deadlines, and conducting meetings. The project director also designs and directs the gathering, tabulating, and interpretation of required data; is responsible for overall program evaluation and staff performance evaluation; delegates assigned responsibilities; and is the responsible authority for ensuring necessary reports and or documentation are submitted to the proper authorities. This position relates to all program objectives.

Evaluation Coordinator

Position Purpose:

Coordinates the process and impact evaluation measures work plan.

Duties and Responsibilities:

The evaluation coordinator, along with other necessary WP staff, develops and maintains all appropriate files, forms, and methods to provide adequate evaluation of the WP impact measures. This position coordinates the reporting schedules and data as well as assesses quality assurance of the evaluation process. The evaluation coordinator is responsible for developing and maintaining accurate and timely records of all outcome components. This position works with the training coordinator and staff to provide evaluation records and assistance as necessary.

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Area Outreach Coordinator

Position Purpose:

Provides support for all planned educational activities at each selected Witness program site.

Duties and Responsibilities:

- Ensures complete logistical arrangements for carrying out program activities, including onsite set-up, food and beverage selections, and pre- and on-site participant registration.
- Coordinates materials to support organizations in their media relations efforts by providing appropriate and timely feedback on Witness program concepts.
- Recruits team members.
- Networks with local group activities that support Witness program activities.
- Collects reimbursement forms for stipends and travel from WRMs and LHAs.
- Provides feedback on program activities, and acts as liaison between team members and Witness Project® staff.

The Witness Project®

- Maintains files, correspondence, and reporting forms used by team members (sign-in sheets, Program Registration Forms, Informed Consent Forms)
- Organizes WP programs to include coordinating travel, transportation, program site location, program time, and publicity
- Acts as liaison between church ministers, *The* Witness Project® and community groups.

QUALIFICATIONS:

The outreach coordinator should possess good communication and organizational skills and have several years of experience in community outreach.

This position may incur overnight and weekend travel within the state to manage and coordinate on-site Witness programs.

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Training Coordinator

Position Purpose:

Provides management and direction in the recruitment and training of WRMs and LHAs.

Duties and Responsibilities:

The Training Coordinator should be certified in BSE and have some experience in adult education or knowledge of adult learning principles. An effective training coordinator should also be able to relate well with recruits, build trust, and have a good knowledge of community-based health education and breast and cervical cancer control issues. In addition, this person:

- coordinates program schedules with the Area Outreach Coordinator
- schedules and provides training for potential WRMs and LHAs
- makes provisions for annual continuing education for WRMs and LHAs who want to sharpen and refresh their skills.

The training coordinator, who must remain proficient in breast-self-examination (BSE) skills, is responsible for teaching BSE to LHAs.

The Training Coordinator ensures that all training supplies are available and intact and all educational literature in use is according to current guidelines.

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Working with the Area Outreach Coordinator, this position maintains records of all training, program activities, and community contacts. The Training Coordinator acts as a resource for the Area Outreach Coordinator.

Navigator

Position Purpose:

Using the Program Registration Form and Follow up Sheet, the navigator (or other designated WP staff or team member) will identify those women who have requested assistance in obtaining breast and cervical cancer screening services and those who are not current in their screening. She will assist them in scheduling their appointments as well as direct them to service providers that in addition to determining eligibility may also provide assistance with transportation; child or adult care; and or provide more information on breast and cervical cancer screening services.

Duties and Responsibilities:

The navigator contacts and encourages women who are in need of clinical services to use resources available in the local health care system. This position acts as the intermediary between local agencies and women by receiving and relaying information regarding eligibility and / or appointments for screening services based on information received. Other duties are:

- Document confidential information pertaining to the request for assistance with breast and cervical cancer screening services.
- Share information about various agencies in the community and how they may be able to meet specific screening needs.
- Determine the agency to be contacted for screening services and make the appropriate referral.

© 2000 The Witness Project® Revised 03/2004 ■ Set up files for each contact and any subsequent follow-ups and maintain this database for retrieval and reporting purposes to the National Witness Project® evaluation coordinator.

Qualifications:

The navigator will have excellent communication skills and several years of experience in community outreach. This position should have a working knowledge of computer skills such as word processing, excel and access software programs, or other database software.

Budget

Examples

The following pages include several budget examples to assist you in determining how much funding your project will need. The National Witness Project® uses the annual expenditure reports collected from sites to determine budget examples. Documenting expenses will also assist you in determining future funding needs.

Consider all items and resources your project will require based on the needs of the priority population you are reaching and future expansion. Your project will require breast models, breast and cervical cancer education literature, TV/VCR, paper, and other supplies. A list of needed items can be found in the section entitled *Project* Partners under Financial Resources Needed.

Do you plan to pay your team members a stipend for conducting programs? How are you going to meet the evaluation needs of your program? These are just a few things to consider as your program evolves.

BUDGET EXAMPLE Shoestring \$0 - \$5,200

Personnel

TOTAL \$0 - in kind

Project Director (25% time) donated Witness Role Models (2) donated* Lay Health Advisor donated* **TOTAL** \$ **Equipment** 1,115 \$ Ethnic breast models (A-B-C Size Set from HealthEdco) 300 \$ MammaCare models (\$150 ea. Plus \$15 s/h) 315 \$ Portable TV/VCR for showing video 500 Travel **TOTAL** \$ 250 Estimated mileage reimbursement to WRM'S/LHA's for \$ training and going to programs (\$.29 - \$.35/mile) 250 **Supplies TOTAL** \$ 600 Cost recovery for BSE and mammography literature from NCI and ACS; and printing 250 Witness Brochures \$ 350 \$ Training expenses (notebooks, page savers, beads, lunch) 100 Refreshments for Witness programs (approx. 15 @ \$10 ea.) \$ 150 Other **TOTAL** \$ 597 Stipends for 3 trainees @ \$8.00/hr. x 8 hrs. \$ 192 \$ Appreciation luncheon for WRM's and LHA's 100 \$ Incentive gifts/gift certificates for 3 WRM's and LHA's 105 Postage, copying and telephone expenses \$ 200 **SUB-TOTAL** 2,562 Other options *Stipends for 2 WRM's and 1 LHA for participating in 10 programs each @ \$40 \$ 1,200 Evaluation (payment by interview to assess BSE, mammography and pap test practice post intervention) 100 telephone surveys @ \$10 each \$ 1,000 \$ or \$15 each 1,500 **GRAND TOTAL** \$ 5,262

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BUDGET EXAMPLE Shoestring \$5,200 - \$25,000

	\$5,200 - \$2	25,000			
Personnel			TOTAL	\$ 14	1,000
Project Director (50%) (Can be in-kind) Witness Role Models (4) Lay Health Advisors (3)		donated* donated*			
Equipment			TOTAL	\$ 1	,265
Ethnic breast models (A-B-C Size Set from Health E MammaCare models (3x \$150 ea. + s/h \$15) Portable TV/VCR for showing video	dco\$ \$ \$	300 465 500			
Travel			TOTAL	\$	250
Estimated mileage reimbursement to WRM'S/LHA's training and going to programs (\$.29 - \$.35/mile) (NOTE: in rural areas this amount will need to be income.	\$	250			
Supplies			TOTAL	\$	800
Cost recovery for BSE and mammography literature NCE and ACS; and printing 300 Witness Brochures Training expenses (notebooks, page savers, beads, lu Refreshments for Witness programs (approx. 25 @\$:	s (s) (s) (s) (s) (s) (s) (s) (s) (s) (s	400 150 250			
Other			TOTAL	\$	1,043
Stipends for 7 trainees @ \$8.00/hr. x 8 hrs. Appreciation luncheon/continuing education meeting	\$	448			
for WRM's and LHA's		150			
Incentive gifts/gift certificates for 7 WRM's and LHA	4's \$	245			
Postage, copying and telephone expenses	\$ A's \$ \$	200			
SUB-TOTAL				\$ 17,	358
Other options: Stipends for 4 WRM's and 3 LHA for participation is	n				
15 programs each @ \$40 Evaluation (payment by interview to assess BSE,	\$	4,200			
Mammography and Pap test practice post interventio		2.500			
250 telephone surveys at \$10 each or \$15 each	\$ \$	2,500 3,750			
GRAND TOTAL				\$ 2	2 <u>5,308</u>

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BUDGET EXAMPLE Regional or State \$25,000 - \$200,000

Personnel

TOTAL

\$ 111,520

				*
Project Director (50 – 100%) (Depending upon the level of expertise and outreach Experience, this postion rages from \$25,000 to \$50,000. See job descriptions) Outreach Coordinator(s) (50% time) (20 hrs/week @ \$8\$10./hr) Training Coordinator (50-100%) Follow-up Evaluator (50-100%) (**May select to contract this per call; see options below) Administrative Assistant/Secretary (50-100%) Witness Role Models (10+) Lay Health Advisors (5+) ***(Salaries are listed at minimal levels for given requirement	\$ \$ \$ \$ \$	25,000 * 20,000 * 18,200 * donated * donated *	**	
require higher wages to adequately fill positions)	,	<i>y</i> -8		
Equipment			TOTAL	\$ 5,635
Ethnic breast models (A-B-C Size Set from Health Edco MammaCare models (8x \$150 ea. + s/h \$35) Portable TV/VCR for showing video (3) Exhibit for recruitment and promotion of project (Includes photography, graphics and display)	\$ \$ \$ \$	900 1,235 1,500 2,000		
Travel			TOTAL	\$ 3,000
Travel Estimated mileage reimbursement to WRM'S/LHA's for training and going to programs (\$.29 - \$.35/mile) Includes overnight stays for training as necessary (can use sta	te rate i	for hotels an		\$ 3,000
Estimated mileage reimbursement to WRM'S/LHA's for training and going to programs (\$.29 - \$.35/mile)	te rate	for hotels an		\$ 3,000 2,300
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Estimated mileage reimbursement to WRM'S/LHA's for training and going to programs (\$.29 - \$.35/mile) Includes overnight stays for training as necessary (can use statement of the stay of training as necessary (can use statement of the stay of training as necessary (can use statement of the stay of training as necessary (can use statement of the stay of training as necessary (can use statement of the stay of training as necessary (can use statement of the stay of training as necessary (can use statement of the stay of training as necessary (can use statement of the stay of training as necessary (can use statement of the stay of training as necessary (can use statement of the stay of training as necessary (can use statement of the stay of the	\$ \$ \$ \$	900 500 650 250	d per diem) TOTAL	\$ 2,300
Estimated mileage reimbursement to WRM'S/LHA's for training and going to programs (\$.29 - \$.35/mile) Includes overnight stays for training as necessary (can use statement of the stay of training as necessary (can use statement of the stay of training as necessary (can use statement of the stay of training as necessary (can use statement of the stay of training as necessary (can use statement of the stay of training as necessary (can use statement of the stay of training as necessary (can use statement of the stay of training as necessary (can use statement of the stay of training as necessary (can use statement of the stay of training as necessary (can use statement of the stay of training as necessary (can use statement of the stay of the	\$ \$ \$ \$	900 500 650 250	d per diem) TOTAL	\$ 2,300

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BUDGET EXAMPLE Regional or State \$25,000 - \$200,000

SUB-TOTAL \$ 110,312

Other options:			
Stipends for 4 WRM's and 3 LHA for p	articipation in		
15 programs each @ \$40		\$	7,200
	D.C.D.		
**Evaluation (payment by interview to	assess BSE,		
Mammography and Pap test practice po	st intervention		
500 telephone surveys at \$10 each		\$	5,000
or \$15 each		\$	7,500
Annual meeting for all WRM's, LHA's	and staff;		
Continuing education and team building	g. Cost		
dependent upon outside speakers fees, to	ravel, overnight		
and number of meetings per year.		\$	4,500
	or	\$	20,000
Travel for staff to attend national cancer	education meetings	s;	
National Witness meetings, etc	per meeting	\$	2,000

GRAND TOTAL \$ 156,512

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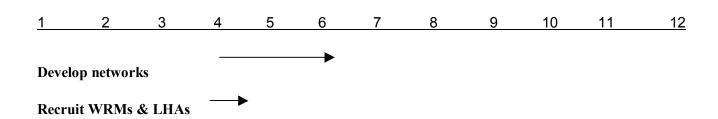
Timelines

We have included timelines for shoestring, moderate, and regional projects. They should give you an idea of the timing for recruitment, training, beginning programs and following up with program participants.

TIMELINE

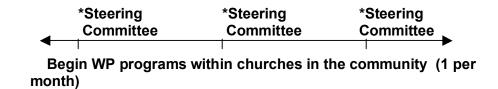
Shoestring

Months









^{*}Steering Committee - Monthly

NOTE: DO NOT schedule training or programs between Thanksgiving and Mid-January.

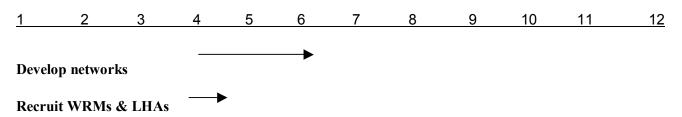
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^{*}Advisory - Quarterly

^{*}Evaluation - Follow up with program participants

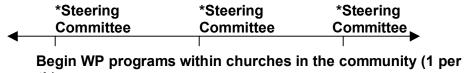
Moderate











month)



NOTE: DO NOT Schedule training or programs between Thanksgiving and Mid-January.

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^{*}Steering Committee - Monthly

^{*}Advisory - Quarterly

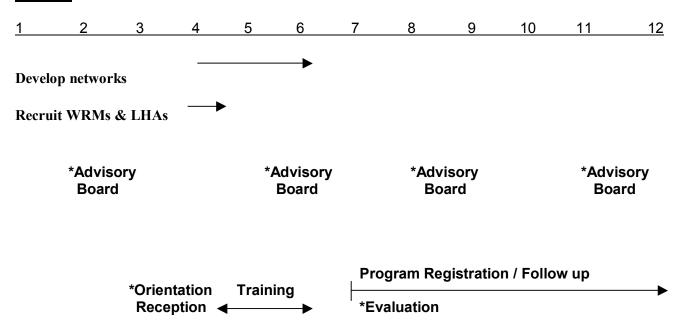
^{*}Evaluation - Follow up with program participants

Timeline (continued)

Regional or State

Year 1







Begin WP programs within churches in the community (1 per month) (target specific counties)



NOTE: DO NOT Schedule training or programs between Thanksgiving and Mid-January.

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^{*}Steering Committee - Monthly

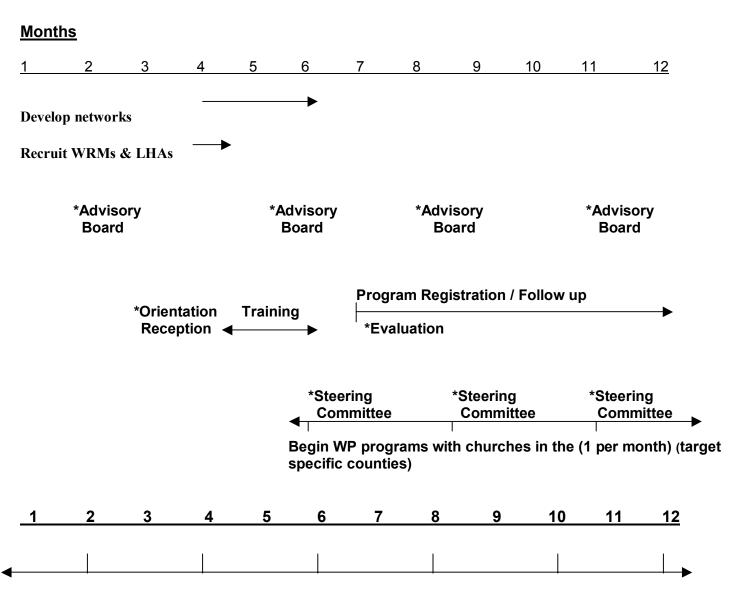
^{*}Advisory Committee - Quarterly

^{*}Evaluation - Follow up with program participants

Timeline (continued)

Regional or State





Training - 6X per year (every 2 months)

NOTE: DO NOT schedule training or programs between Thanksgiving and Mid-January.

The Witness Project®

^{*}Steering Committee - Monthly

^{*}Advisory Committee - Quarterly

^{*}Evaluation - Follow up with program participants

