LAY HEALTH ADVISER (LHA) TRAINING MANUAL
FOR FAITH MOVES MOUNTAINS PROJECT:

MANUAL CONTENTS

SECTION 1
- Background & overview: Faith Moves Mountains (FMM) project
- Cervical cancer and Pap tests
- HPV info
- What are lay health advisers (LHAs) and how are LHAs a part of FMM? Examples of 3 LHA projects.
- Contact list
- List of supplies and materials

SECTION 2
- Human subjects
- Information and power point presentation
- Test for review

SECTION 3
- What will the LHAs be doing?
- Checklist on what to take with you to session
- Steps to take for the session
    - Scripts for sessions:
    - 1. First telephone/visit contact and reminder
    - 2. Home visit
- Tailored newsletters
    - 3. Follow up calls
- Tips and techniques
- Thank you notes
- Feedback and journals

SECTION 4
- Financial documents
- Procedures for payment
- Feedback and check-ins

Faith Moves Mountains (FMM) was sponsored by the National Cancer Institute R01 CA108696.

LAY HEALTH ADVISER (LHA) TRAINING MANUAL FOR FAITH MOVES MOUNTAINS PROJECT

SECTION 1

Background & overview: Faith Moves Mountains (FMM) project
Cervical cancer & Pap tests
HPV info
What are lay health advisers (LHAs) and how are LHAs a part of FMM? Examples of 3 LHA projects.
Contact list
List of supplies and materials

BACKGROUND AND OVERVIEW OF THE PROJECT

Approximately 13,000 new cases of invasive cervical cancer are diagnosed each year, with 4,600 deaths resulting annually from invasive cervical cancer. These numbers represent a 75% reduction from the previous five decades, attributable to the proliferation of Pap smear screening and to improvements in post diagnosis treatment.

Despite this encouraging reduction, certain groups of women have not experienced such significant benefits and remain at disproportionate risk for cervical cancer. Among these women are those living in rural areas, particularly Appalachian middle aged and older women. To reduce the unequal and unnecessary burden from cervical cancer experienced by rural women, this study proposed to undertake a community participatory, tailored, faith-based intervention. While extensive literature has established the association between rural culture and religiosity, aside from successful African-American programs, surprisingly few scientifically-based interventions have located health promotion and disease prevention activities within rural religious institutions. We intend to taken advantage of this unique connection among the disproportionately affected rural populations and trusted, sustainable, local religious organizations by employing an innovative, pretested, and theoretically based intervention program. Thus, the broad, long-term objective of the proposed project is to reduce the disproportionate cervical cancer burden experienced by rural Appalachian women by increasing the use of Pap smears and follow-up treatment after abnormal screening results. To achieve this objective, the following specific aims are proposed:

(1) To examine the factors (both barriers and assets) that influence the use of Pap smear screenings and appropriate follow-up procedures among rural women.
(2) To administer a faith-based, community-participatory, theoretically informed, and culturally consistent intervention to increase the use of Pap smears and appropriate follow-up procedures.
(3) To evaluate the efficacy of the group-randomized tailored intervention.

The results from the project will enable position researchers and communities to: address the real and perceived barriers that prevent rural women from receiving Pap tests; draw on local community assets to promote the use of Pap tests; and establish a model that can be extrapolated to other rural, underserved communities for cancer prevention. Other implications of the proposed project include enhancing the capacity of local communities to develop, organize, and administer health promotion protocols that adhere to both community and scientific standards and reducing the unnecessary and disproportionate health burdens experienced by rural residents, particularly those in the older age groups.

What is cervical cancer?

Cervical cancer is a disease in which malignant (cancer) cells form in the tissues of the cervix. The cervix is the lower, narrow end of the uterus (the hollow, pear-shaped organ where a fetus grows). The cervix leads from the uterus to the vagina (birth canal). Cervical cancer usually develops slowly over time.

Human papillomavirus (HPV) infection is the major risk factor for development of cervical cancer

Other possible risk factors include the following:

- Giving birth to many children.
- Having many sexual partners.
- Having first sexual intercourse at a young age.
- Smoking cigarettes.
- Oral contraceptive use ("the Pill").
- Weakened immune system.

What is a Pap test?

Doctors use the Pap test to see if there are any cell changes. The Pap test looks at a sample of cells from your cervix to see if there are any cells that are abnormal. The Pap test is a good way to find cancer cells and cells that might become cancerous in the future. The Pap test can be performed as a normal part of a routine pelvic exam. The doctor uses a small, soft brush to collect cervical cells. The cells are sent to a lab, where they are examined under a microscope.

Who should be tested?

All women who are or have been in a sexual relationship and have a cervix.

How often should women be tested?

Women should be screened for cervical cancer about 3 years after they start having sexual intercourse. Screenings should start by the time a woman is 21 years old.

Women should be screened every year until they have two or three normal pap smears in a row. They should then be screened at least every three years until age 65 to 70.

According to ACS, women age 70 and older who have had 3 or more normal Pap test results in a row and no abnormal test in the last 10 years don't have to get a Pap test again. Since there has not been a lot of research on the risks that older women have of getting cervical cancer, ACOG recommends that women over the age of 70 should still get Pap tests every 2 or 3 years. Talk to your doctor to decide the best plan for you.

Should you be tested if you had a hysterectomy?

The answer to this question depends on why you had a hysterectomy.

- If you had a hysterectomy to treat cervical cancer, you should continue to have regular Pap tests to make sure the cancer hasn't come back.
- If you had a hysterectomy to treat pre-cancerous changes in your cervix you should continue to have regular tests for at least a few years after the surgery.
- If you had a hysterectomy to treat uterine or ovarian cancer, your doctor may advise you to have Pap tests regularly, since the tests are helpful in finding recurrences of these cancers.
- If you had a hysterectomy where your cervix was not removed (called a subtotal or supracervical hysterectomy), you should have regular tests until you are at least 70 years old. Since your cervix wasn't removed, there is still a chance you could develop cervical cancer.
- If you had a total hysterectomy (the entire uterus, including the cervix was removed) for a reason other than cancer or pre-cancer, you may not need to have the Pap or HPV test any more. Check with your doctor first, since some conditions may mean that you should continue to be tested.

A Few Things to Remember

- The single most important thing that a woman can do is to participate in a regular screening program. All women who are screened enjoy a dramatic reduction in the risk of cervical cancer compared to women who do not get tested. Make you appointment today!
- Most cervical cancer is preventable. Early detection of abnormal cell changes is important. Cervical cancer is rare and almost always prevented through regular screening and treatment of pre-cancerous changes.

What are Lay Health Advisers?

- LHAs are “natural helpers” who provide education and develop and promote activities designed to reduce the risk factors for disease.
- LHAs are individuals in the community who have a reputation as a "natural helper" and are trusted by their friends, family, and neighbors.
- LHAs can foster behavior change, especially in underserved populations, by bringing practice advice and down to earth information about health issues.

Lay Health Advisers (LHA) and Faith Moves Mountains:

We decided to use a LHA approach because we know that LHAs not only can serve to educate women on the need for Pap smears and appropriate follow-up, but can decrease distrust about the health care environment and even provide suggests on ways to overcome common barriers.

LHA interventions have been shown to be especially useful for hard-to-reach populations, including the 20-30% of women who don’t get screened for cervical cancer. A lot of these women lack physician referrals, educational enrichment, and positive patient-physician communication. They may face large transportation problems, childcare commitment, or are just nervous around doctors.

LHAs are very useful because many underserved women have been shown to draw heavily on the input from their peers, thereby enhancing the utility of LHA programs. For rural women, LHAs have been particularly helpful to tailor area resources and information to specific community barriers. For example, the North Carolina Breast Cancer Screening Program (NC-BCSP) trained LHAs and community outreach specialists not only to convince women about the importance of mammogram, but also to provide informational and instrumental support on obtaining free or low cost screenings

Here are some examples of LHA programs in other places:

NC-BCSP Lay Health Advisors

One important aspect of NC-BCSP is its community-based health education program based on a network of more than 140 lay health advisors (LHAs). NC-BCSP LHAs are older African American women working within their local communities to encourage friends, families, and others they meet to have regular mammograms and pap smears.

The LHAs stay quite busy. They coordinate and lead a variety of breast and cervical cancer education campaigns at local churches, businesses, and community events. Often these campaigns center around some special occasion, such as Mother's Day, Valentine's Day, or Breast Cancer Awareness Month.

The lay health advisors are all volunteers who have received training on breast and cervical cancer, as well as the benefits of mammography and pap smears. They offer their time and energy because they care about the women in their communities, and want to help spread the word about early detection. Please follow the links below to read more about LHAs and to see pictures of some LHAs in action.

REACH 2010 program:

The Lay Health Advisors (LHAs) are a cornerstone of the Charlotte REACH 2010 Project. The LHA Program identifies and recruits residents who live within 14 neighborhoods of northwest Charlotte. LHAs are “natural helpers” who provide education and develop and promote activities designed to reduce the risk factors of cardiovascular disease and diabetes. Neighborhood residents are employed as LHAs to promote positive health behaviors among their neighbors. LHAs educate, motivate, refer and encourage their neighbors to improve their health and overall quality of life. Peer education through one-on-one visits, mentoring, acting as a referral source and role model and facilitating neighborhood activities are ways in which LHAs encourage healthy lifestyle changes. Lay Health Advisor-facilitated initiatives and activities include:

- Diabetes and Hypertension Support Groups
- Grocery Store Tours
- Health Fairs
- Healthy Cooking Demonstrations
- Neighborhood Walking Groups
- Exercises Classes (coming soon!)

LAY HEALTH ADVISERS IMPROVE WOMEN'S USE OF MAMMOGRAPHY

COLUMBUS, Ohio – The number of rural, low-income women who choose to get mammograms may dramatically increase if those women get their health information from trained lay advisers in their own community, a new study shows.

The effect was consistent across the three racial groups included in the study.

“Our results show that lay health advisers can improve the rates of mammography screening among low-income, rural white, African-American and Native American women,” says principal investigator Electra D. Paskett, who is a professor in the College of Medicine and School of Public Health at Ohio State.

Regular mammograms and clinical breast exams can detect breast cancer early and reduce mortality from the disease. But mammography is underused by certain groups of women, particularly rural, poor and minority women. Such women typically fall into the category of “rarely or never screened” for cancer and are considered high-risk populations, said Paskett, associate director for population sciences at the Ohio State University Comprehensive Cancer Center – Arthur G. James Cancer Hospital and Richard J. Solove Research Institute.

The goal of this study was to increase awareness of the benefits of early breast-cancer detection, encourage women to seek breast-cancer screening and to identify and reduce barriers that kept women from getting mammograms.

The four-year study began in 1998 in rural North Carolina, said Paskett. She began the work while at the Wake Forest University School of Medicine before coming to Ohio State in 2002.

The study involved 851 rural, low-income white, Native American and African American women, ages 40 or older, who had not gotten a mammogram in the past year. Each woman completed a survey about her knowledge and use of breast- and cervical-cancer screening.

The participants were randomly assigned to either a group that received home visits from a lay health adviser or to a comparison group.

The comparison group received a letter and a National Cancer Institute brochure about the need for regular cervical cancer screening. Women in the intervention group received three in-person home visits over a nine- to 12-month period.

> ***“The intervention improved knowledge and beliefs about mammography screening. We empowered these women to realize that they can schedule a mammogram on their own, with or without encouragement from their doctors.”***

During the home visits, the lay health advisers discussed mammography, breast cancer, breast self-exam and scheduling a mammogram. They also provided educational materials about cancer risk and how to obtain mammograms. Follow-up phone calls were made to help participants make mammography appointments and to encourage women to discuss their mammogram experiences.

After12 to14 months, participants were asked to complete a follow-up survey. The researchers also checked medical records to verify rates of mammography use.

Three months after completing the follow-up survey, women in the comparison group were sent a letter inviting them to obtain a free mammogram, along with a brochure about mammography from the National Cancer Institute.

Barriers identified by the study that most often kept women from receiving mammograms were perceived cost (54 percent) and lack of encouragement (45 percent), and the beliefs that radiation from the procedure cause cancer (41 percent) and that mammograms hurt (41 percent). The women could cite more than one barrier.

In all, 42 percent of the women in the LHA group received a mammogram vs. 27 percent in the control group, resulting in 66 additional mammograms.

“The intervention improved knowledge and beliefs about mammography screening,” said Paskett, who is also a professor in the School of Public Health.

“We empowered these women to realize that they can schedule a mammogram on their own, with or without encouragement from their doctors.”

Funds from the National Cancer Institute supported the study.

CONTACT INFORMATION FOR FMM

1. For most of your questions about the project, including forms, payments, supplies, feedback, etc. please contact:

2. For questions about the session techniques, overall project conduct, please contact:

3. For questions about human subjects, please contact:

4. For questions about the tailored newsletters, please contact:

LISTS OF SUPPLIES, DOCUMENTS, QUESTIONNAIRES, MISCELLANEOUS

1. Supplies for the project

- Training manual, including human subjects materials
- Pad and pen

2. Documents

- Financial documents:
    1. Independent contractor form (interviewers)
    2. W-9s (interviewers)
    3. Sample invoice
    4. Request for compensation form (participants)

3. Sample tailored newsletter

4. Journal

LAY HEALTH ADVISER (LHA) TRAINING MANUAL FOR FAITH MOVES MOUNTAINS PROJECT

SECTION 2	Human subjects Information and power point presentation Test for review

HUMAN SUBJECTS PROTECTION

This educational module will help you identify research activities that involve human participants and help you understand how to protect the rights and welfare of all human participants involved in research.

Upon completion of this course, the learner will be able to:

- ✓ *Identify the three fundamental ethical principles that guide the ethical conduct of research involving human participants*
- ✓ *Define privacy and confidentiality as it applies to protecting human participants and describe how these can be maintained throughout the research process*
- ✓ *Define informed consent*
- ✓ *Define conditions under which informed consent may be withdrawn.*

Overview

When human participants are involved in research studies, the researchers and the research team has an obligation to protect them and their personal information.

The ***human participant*** is a living individual about whom a researcher obtains private information. This private information is sensitive and confidential. That includes information that may not seem private, such as the fact that they are participating in a research study. However, all information regarding persons involved in the study is to be regarded as confidential and should be kept secure and protected.

In the course of participating in a research study, a person may provide information to you, the interviewer, about other persons, such as a spouse, relative, friend, or social acquaintance. The information may be sensitive (e.g., regarding alcohol or drug use, diet, or lifestyle) and personal. Interviewers should treat all information about individuals or other persons they talk to you about as confidential. Identifying information, whether about a human subject or a third party, should be kept secure and protected.

Researchers and the research team have a fundamental responsibility to safeguard the rights and welfare of the people participating in their research activities.

Emphasis on enhancing protection is needed to:

- Promote the safety and well-being of human participants in research.
- Maintain the ethical values and principles underlying research.
- Address concerns by the general public about the responsible conduct of research.

The three fundamental ethical principles that guide the ethical conduct of research involving human participants are:

1. **Respect for Persons (autonomy)**
2. **Beneficence**
3. **Justice**

Respect for Persons

Individuals should be treated as autonomous agents.

> "An autonomous person is a person who can make decisions for themselves and act on those decisions. To respect the person is to give them the chance to make those decisions and not act to block those choices.
>
> Persons involved in a research study must be given the information they need to decide whether or not to participate in the study. There should be no pressure to participate and plenty of time to decide. Respect for persons demands that participants come into the research study voluntarily and with complete information. This is called *informed consent.*

Beneficence

People in the study are treated in an ethical manner not only by respecting their decision but also by protecting them from harm and looking out for their well being.

The principle of *beneficence* obligates the researcher to benefit the persons as much as possible and harm them as little as possible.

While the goal of doing the research study is to benefit the public, individuals should not be purposefully harmed in order to reach that goal.

Justice

The ethical considerations of risks versus benefits leads to the question of *justice*. This principle requires that people be treated fairly and involves questions such as: Who should bear the risks of research, and who should receive its benefits?

The concept of justice may be questioned when deciding who will be given an opportunity to participate, who will be excluded, and the reasons for exclusion. Justice requires fairness in the research study.

These three ethical principles are the basis for protection of persons involved in research studies. They promote the safety and well being of the participants.

The principles served as a guide in the design of the study, the approval of the study by the institutional review board and should guide you in your conduct of the interviews during the course of the research study.

Informed consent in research is when researchers get the signature of the participants giving them permission to include the person in the study. However, it means more than simply obtaining the persons signature. It is a process that involves giving true information about the study and its purpose; admitting any risks, benefits, alternatives, and procedures; answering questions; and allowing persons to make informed decisions about whether to participate.

In order for consent to be valid, it should be based on the following:

- The participant must be COMPETENT to begin the informed consent process. If the participant is not competent because of age, illness, incapacity, or any other reason the participant may not be included in the research.
- The research team must DISCLOSE all information to the potential participant. The information must be sufficient to allow the potential participant to decide whether to participate. This includes: the purpose of the study; how it will be done; alternatives to the study; and risks, benefits, and uncertainties of each possible part of the study.
- The participant must COMPREHEND the information. The team must know that the person understands what the study is about.
- The participant must AGREE to participate in the research study.
- The participant's agreement must be VOLUNTARY.
- Finally, participants must be informed that even after they have made a voluntary agreement to participate in the study, they may WITHDRAW such agreement at any time without penalty.

Informed consent is communication process that continues during the entire study. Many of the elements of informed consent previously discussed apply throughout the study. As an interviewer you should:

- Feel confident that the participant maintains the ability to understand information, make an informed decision, and voluntarily continue to participate.
- Be satisfied that the participant understands the information provided, has had an opportunity to discuss the information and ask questions, and understands that he or she may withdraw from the study at any time.

If a person chooses to withdraw before, during or after the interview, they should be told that it is ok and there is no penalty involved. They should be assured that the information they have given, if any, will be destroyed and not used for any purpose. They may be given the telephone number of the principle investigator if they have additional questions regarding their withdrawal or need to discuss issues regarding informed consent.

Privacy

Privacy is when a person has control over how, when and where to share information about themselves with others. When participants in research give information about themselves to the research team or institution, they do so in a relationship of trust. They expect that information to be shared only as necessary. The research team must respect the participant's trust and not betray the confidence placed in them. *Privacy* has also been defined as freedom from unwanted intrusion. This means that persons have the right not to share certain information about themselves and the right to prevent others from getting their personal information.

Our goal, as members of the research team is to protect the participants privacy and their personal information from anyone they have not given permission to have access to this information. This includes our own families, friends and others in the community. This includes the fact that the person is involved in a research study. Their inclusion is private as well as any information they give during the study.

Confidentiality

Confidentiality pertains to the treatment of information an individual has given in a relationship of trust and with the expectation that it will not, without permission, be shared with others who are not involved in the research study. The research team uses the information gathered to conduct research only. The ways we can ensure that confidentiality is maintained are:

- Using codes for identifiers (using numbers rather than names on our interview sheets or papers)
- Removing identifying information (such as names and addresses) from interview sheets containing data
- Properly disposing of computer sheets and other papers and the files on computers and discs used to store information
- Limiting access to identifiable data (at homes and offices)
- Storing records in locked cabinets or assigning security codes to computerized records

Breaches of confidentiality are usually defined as giving out information to third parties, without the person's consent or a court order. This can be done by mouth or on paper, by telephone or fax, or electronic-for example, by e-mail.

HUMAN SUBJECTS TEST

***Match the items below with their appropriate descriptions*.**

A. Justice
B. Beneficence
C. Respect for Persons

1. Participants should be treated fairly.

2. Individuals should be capable of making decisions and those decisions should be honored.

3. Persons in the study should not be harmed and should benefit if possible.

Mark the following statements true or false:

4. A participant can end his or her participation in the study at any time, without any negative consequences or explanations.

5. A LHA's casual conversation about a study participant with someone other than the investigator is a breach of confidentiality.

6. An informed consent can be given orally without written documentation.

7. Once a study has begun a participant must answer every question asked.

8. A person may withdraw from the study without written documentation.

9. A LHA may tell her family whom she is talking with as long as she doesn't tell what the participant said.

10. The name and address of the person you are talking with should be kept separate from the interview information.

The following are case studies. Mark the appropriate answers from the multiple-choice questions that follow the case study.

You have just completed a session with Ms. B. Her neighbor spots you leaving her home. The neighbor has heard about the Faith Moves Mountains research study at her church and is curious about who is in it and how it works. Later you run into that neighbor in the grocery store and she asks you if Ms. B is part of the Faith Moves Mountain research study.

11. What would be the most appropriate action to take?

a. Tell her all about the Faith Moves Mountains study and Ms. B's part in the study.
b. Tell her about the Faith Moves Mountain study and where she can get more information if she is interested in participating, but let her know that the names of people participating is confidential information.
c. Act like you didn't hear what she said and keep shopping.
d. Tell her that you can only share that information with her if she participates in the project.

You are entering information on your laptop at home regarding a research participant. Your young son asks to use the computer to play games.

12. What action would be appropriate to protect the confidential information you entered?

a. Ignore your son and keep working.
b. Use a password to protect the information and to avoid unauthorized computer access.
c. Allow your son to play the game as long as you are in the room.
d. Explain to him that this is a work computer and not a family computer.
e. Both B and D.

You had sessions with several ladies in one afternoon. After you arrive home one of those ladies calls and tells you she has decided not to participate. She doesn't give you any reason just says she no longer wants to be in the study.

13. What would be the best action to take?

a. Ask her why she doesn't want to participate so you can try to help her decide.
b. Try to convince her that participation in the study is good for the community. Discuss the pros and cons of participating in a community based research project.
c. Thank her, give her the project manager s number in case she has further questions and assure her you will destroy any information she has given so far.

You are in a women's church group meeting. One or two of the other LHAs are present. The other LHA approaches you and begins to discuss her interviews and what a wonderful success they have been. She asks you if anyone of your ladies has gotten a pap smear after her session and starts to share information about one of her successes.

14. What would be the most appropriate way to continue this conversation?

   a. You tell the other LHA that a women's church meeting is not a good place to talk about this and remind her that private information from research subjects is shared with the team on a necessary basis only.
   b. The other LHA is a part of the research team so you can talk freely about the interviews. It might be helpful to talk about interviewing techniques and information. You continue to listen and share your information as well.
   c. Act like the other LHA didn't say anything and continue to enjoy the church meeting.

You are about to go out and interview Mrs. C and you realize you don't know how to get to her house. Your husband is home and has a really good sense of direction. He is pleased that you are a part of the research team and would be eager to help by giving you an idea of how to get where you are headed.

15. What would be the most appropriate way to get directions to this lady's home?

   a. Ask your husband. Give him the address but not the woman's name and let him tell you how to get there.
   b. Don't do the interview. It must be too far out of the way.
   c. Call the woman and ask her for directions or call the project office and ask Project manager for help.

LAY HEALTH ADVISER (LHA) TRAINING MANUAL FOR FAITH MOVES MOUNTAINS PROJECT

SECTION 3 What will the LHAs be doing?

- Checklist on what to take with you to session
- Steps to take for the session
    - Scripts: 1. First telephone/visit contact and reminder
    - 2. Home visit
- Tailored newsletters
    - 3. Follow up calls
- Tips and techniques
- Thank you notes
- Feedback and journals

What will the LHAs be doing?

<u>Tailored home visit session</u>: A month or so after our last visit with the participant, women will be sent a letter thanking them for participating in the interview and telling them that a LHA will contact them about setting up another home visit in the next two months.

This home visit will consist of a session tailored to getting a Pap test or follow-up if the Pap test was abnormal, her knowledge and literacy level, and to her barriers/assets in obtaining cervical cancer services. The LHAs will contact women by telephone or through meeting at church (if a telephone is not available) to schedule a visit. Six attempts to contact women will be made, varying time of day and day of week. LHAs will return the names and telephone numbers for women who cannot be contacted or scheduled to the project director who will record all enrollment information.

After the LHA and participant agree upon an acceptable date for the home visit, the session will proceed as follows: the LHA will briefly review the educational curriculum provided, with the assistance of a flip chart. Following this opening segment, the LHA will then present the participant with her personalized newsletter. The tailored, educationally-appropriate newsletter will be designed according to information obtained during the first interview (i.e., barriers/assets).

The Faith Moves Mountains (FMM) newsletter will be approximately four pages in length. The newsletter will be tailored according to: (1) the participant's particular cervical cancer activity challenge (Pap smears or follow-up treatment) and (2) the barriers and assets indicated by the participant during the baseline interview.

The LHA will spend 30 minutes reviewing the newsletter with the woman during the home visit. Then, in conjunction with the LHA, each woman will create her own specific action plan to be recorded on the form adjacent to each barrier listed. If the participant agrees, the LHA will provide assistance in calling the woman's health care provider or low cost/free health clinics and making the appointment before exiting the home, if appropriate. The standardized form will include space to record the time, date, and location of the visit. Following completion of the action plan form, the LHA will distribute a card that will list a number of local screening providers, several bulleted messages encouraging a visit to a health care provider, and the names and locations of the contact person for each and telephone number. The LHA will then thank the participant, encourage her to follow-through on her action plan, and give her a copy of the action plan. Following this home visit, the LHA will mail a tailored thank you letter to the participant, reinforcing the need to visit her health care provider. This tailored thank you letter will bullet key highlights from the visit, including acknowledgment that a specific action plan was developed.

Checklist of items to bring to home visit session:

- ☐ This binder
- ☐ Pen
- ☐ Legal pad
- ☐ Hard copy of script (see pages below)
- ☐ Research participant compensation form
- ☐ Name, phone number and directions to the home of the person to be interviewed (if applicable)
- ☐ Phone number of Faith Moves Mountains office

Steps to take for the session

Script 1 First telephone/visit contact

Hi, my name is __________, may I please speak with ***(Insert name of participant***)?

Hi (***Insert name of participant***) my name is __________, and I'm with Faith Moves Mountains, located in XXX. Our project works with University, the National Cancer Institute, and our local communities in XXXX counties. Is this a good time to talk?

(If not, ask when to call back)

You may remember talking with other people ***(state the name, if possible)*** from our project a few months ago. They asked you a bunch of questions, told you a little bit about cervical cancer, and said that we would be contacting you again. Well, I wanted to ask you for just a little bit more of your time to do something that I think you'll find fun and interesting.

We're setting up meetings that would probably be no more than an hour long—I'd come to your home or wherever you would like to meet and we'd talk about the questions that you answered, your health, and some of the things that make it hard for you to get the care you need. Like last time, we would pay you for your time.

I've got quite a few days and times open and I want to make this convenient for your schedule. Could we meet on ____________________ ***(suggest a date and time)***?

Great! I'm really exciting about visiting with you. I'll give you a call the night before to remind us both and make sure I have the directions right.

Script 1a) Reminder call

Note: The night before you are going to an appointment, call the participant (up until 9 pm unless she tells you otherwise). Try early and keep trying. If you can't get them in that evening, or if she sounds a little unsure, call several hours before you have the appointment. Say something like:

Hi! This is ________from Faith Moves Mountains. I'm calling to confirm our meeting tomorrow at your house ***(say address)*** at (***say the time***). Again, I'd be there mo more than an hour and you'll receive a payment from us. Is this ok with you?

(<u>If yes</u>: ***Great! I'll look forward to seeing you tomorrow***.)

<u>If no:</u> ***Oh, I'm sorry that won't work for you. Let's get together at a different time. Would ____ (time and day) work for you?)*** Remember to call the night before the rescheduled meeting.)

Script 2: Home visit session

Note: You will be talking with the participant first about cervical cancer and then leafing through the tailored newsletter, and answering questions. Start off your session with some chatting and be sure to go to a quiet, private place where you can speak openly.

1. Ask the person if she has any questions before you begin.

2. Go through the flip chart, stopping now and then to answer questions.

3. Now onto the newsletter. Go through the newsletter page by page, reading it with the participant.

4. Action plan: After you complete the newsletter review, it’s time to complete the action plan form.

5. Closing the interview: At the end of the interview, fill out the research compensation form for the $25 payment and explain how payment is made. The checks are run through UK, but since they are under $200, they will not be reported to the IRS. The respondents can expect to receive a check in 4-6 weeks. Sometimes payment comes earlier. If they haven’t received a check in 6 weeks, ask them to contact you or Project manager

6. Thank the participant for their time. Ask if they have any further questions and tell them that you will check back with them within 2 weeks. But emphasize that they can reach you or Project manager if they have questions.

Tailored Newsletters:

The tailored, educationally-appropriate newsletter will be designed according to information obtained during the baseline interview (i.e., barriers/assets). Dr. Dignan will lead the tailoring of the newsletter. Here are the parts of the newsletter:

Page 1: Brief introduction to the FMM tailored newsletter with the LHA listed as the information source (with insert photograph of LHA or church). The introduction will briefly review the contents of the newsletter. In addition, a column will be written by one of the LHAs with a testimonial about the importance of cervical cancer screening and or follow-up.

Page 2: A question and answer column from Dr. XXX will provide information about the need for screening, the recommended cancer screening tests and guidelines for screening, and the advantages of screening.

Page 3: A half-page layout highlighting the most important barriers reported by the participant in the baseline interview will be provided in bullet format, followed by a half page providing strategies for overcoming barriers. For example, if cost, transportation, and/or child/elder care are significant barriers for the woman, we will list community services and contact information. For women who list no barriers, the newsletter will discuss the most common barriers to screening.

Page 4: A half-page column written from the point of view of the health department or other contact person (with photograph insert) who is responsible for making appointments for cervical cancer screening.

This column will provide a description of the process of making an appointment, identify phone numbers, and explain how the appointment can be made. The remaining half-page will be reserved for a final message by the LHA (with a signature byline) that will include Biblical references or faith-related language.

Script 3: Follow up calls

Note: After 2 weeks, please call or visit back with your participant. This will be a call to make sure that your participant has no questions about what you went over during your visit and has made progress with the action plan that you developed.

Hi, my name is __________, may I please speak with ***(Insert name of participant***)?

Hi (***Insert name of participant***) this is __________, from Faith Moves Mountains. Is this a good time to talk?

First, I wanted to tell you what a nice visit I had with you ***(a couple of Tuesdays ago, etc.).***

I wanted to check in with you to see if you had any questions about anything that we went over during my visit.

(answer questions or, if you are not sure about something, let them know that you will find out the answer and get right back with them).

I also wanted to see if you needed any help with the action plan that we set up ***(remind them of what this consisted of—you might say something like, "I was wondering if you were able to make that appointment with LKLP to get you to the clinic. Is there anything that I can do to be helpful?")***

Thank them again for their time.

Background to FMM home visits, tips and techniques

You, the LHA, play a huge role in this project. You have been selected for this position, in part, because of your ability to communicate well with others. You have probably done some interviewing and maybe home visits in your life and have good experience. These tips and techniques are designed to help you with issues that you may face during this particular project.

Avoid the following:

1. Being too insistent: We want to make sure that the participant schedules (has eventually has) a Pap test, but we also have to realize that she may have a lot going on and Pap tests may not be the first priority. As Project manager says, we like to emphasize that Pap tests are easy steps to a peace of mind.

2. Rushing the participant: Some people take a longer time to decide that they are ready to have a Pap test than others. If, during your visit, you sense that the participant still does really not want to get a Pap test, ask her what is on her mind or tell her that you sense some unease and see what you can figure out. Maybe she just needs a little time to let this all sink or, or maybe she needs you to help her make the appointment.

3. Never share someone else's responses with your current respondent

4. Be sure the participant gets to talk too—You are the one bringing her the message, but you need to hear her concerns and address them.

Try always to:

1. Go through the scripts and steps of the home visit in their entirety

2. Read the newsletter a couple of times before a home visit so you are not reading it line by line with the participant: We think that you and the way that you go over the newsletter may change women's minds about getting Pap tests. It's really important, then, to know the content of the newsletter, be able to answer questions about Pap tests, cervical cancer, services in the community (or, if you don't have that information, to find it out later and tell them), and to make this interesting for the participants. If you read them the newsletter, they will get bored and maybe even insulted. So, practice going through the newsletter, being complete with the information, but excited.

3. Offer to repeat any part of the newsletter and answer any questions if you feel that they are misunderstood or misinterpreted by the respondent. Participants may need to go through a certain issue more than once.

Other tips:

- You will not understand or even like all participants equally, but that doesn't mean you can't have good sessions with most of them. Here are some hints:

- Mindset: realize that no, not everyone is like you—that everyone is struggling with something that seems monumental and that all people employ different ways of coping with their struggle.

- Stay neutral: it is important not to try to even attempt to change the perspective of the respondent. This may mean avoiding discussions of religion, money, politics, child rearing strategies, etc. It is your place to provide them with information about cervical cancer and Pap tests.

- Do not assume that because you don't look like or speak like or have the same background as the respondent, you won't be able to have an excellent interview. On the other hand, don't assume that just because you go to the same church, grew up close to them or know all their family, you can guess their perspectives.

- Realize that what you are doing may save the life of a woman or several women. The spin off of your work can be huge—families get to have their mothers and grandmothers, sisters, etc. Don't give up even if someone seems stubborn—just letting them know that you care matters a lot.

- If someone is skeptical, you may need to try to convince them that 90% of those women who have abnormal cervical cancer tests will survive if the cancer is detected early. Even if it is detected late, the chances of survival are excellent. The big problem comes when the cancer is not detected. This leads to death.

- Remind the worried participant that her responses are confidential

- Once in a while, someone you talk to in a home visit will demand resources from you that you cannot provide. These resources may be in the forms of materials (money, food etc.), information (please sign me up for a medical card) or services (will you give me a lift to…can you stay and talk a while). Your judgment comes into play here. Some tips to remember:

    - While you are there to "do a job" you are also there as a representative of FMM and, theoretically, because you are concerned about these issues. Plus, you will see these ladies in your community!
    - By the same token, you probably can't and don't want to foster an inappropriate and dependent relationship
    - You might want to use of some of the following statements, for sensitively reminding the participant of your role in their life.

- "I understand how money is tight for you right now. I do wish that I could help, but I'm afraid I cannot" (no need to explain why).

- "I really wish that I knew more about the program, but I do have a telephone number that we can call to see if you are eligible for the program."

- "I will find out more about that program and give you a call tomorrow."

Getting going: some departing thoughts

When you have finished your home visit, it is time to close the meeting. Some important points to remember:

1. Fill out all financial documents
2. Thank them for their time
3. Review the action plan.
4. Provide them with your and the FMM telephone number that they can call if they want additional information or have any further questions.
5. Explain to them that you'll be contacting them in 2 weeks for any questions and in a couple of months for a follow up interview which, like this session, will be paid.

Thank you notes:

Upon completion of the tailored intervention, LHAs will send participants a thank you note and will indicate that an interviewer will be contacting them for a second interview in the next two months.

Feedback:

Project manager will schedule regular meetings with the LHAs to make sure any questions, concerns, and issues are being addressed. However, you should not wait until these meetings to bring up concerns or questions. Please contact Project manager or The PI with any questions immediately. We will find someone who knows the answer to your question.

Project manager and The PI will also provide regular feedback on quality improvement which should help increase your visit skills. In addition, as we do in all of our projects, we will be conducting interviews with some of the women who you see to double check on any information collected and to get your suggestions on how we might improve our work.

Journals: We will provide you with a journal for record keeping purposes and to help remind you of questions and concerns to address during our team meetings. Take the journal with you to your home visit and include the following information:

Name/code # of participant:

Address/directions/telephone #:

Best/worst time to call:

Special needs/considerations:

Main barriers to Pap tests:

Impression of home visit:

Questions or concerns about the visit:

Things to do for follow-up:

LAY HEALTH ADVISER (LHA) TRAINING MANUAL FOR FAITH MOVES MOUNTAINS PROJECT

SECTION 4

Financial documents

1. Independent contractor form (interviewers)
2. W-9 (interviewers)
3. Sample invoice
4. Request for compensation form (participants)

Procedures for payment

SAMPLE INVOICE

Name
Address
Social security number

Date

Invoice for tailored home visit (LHA) services

___# of sessions@ $50 per session= $ total

Project Name: **Appalachian Cervical Cancer Prevention Project**

Account#:

PI’S signature:

____
The PI

Research Subject Payment

Date: ________________________

Name:
____

Address:
____

City _________________________ State __________ Zip Code
____

Payment amount: $25.00

Investigator/Interviewer:
____

PI:

Project Name: **Appalachian Cervical Cancer Prevention Project**

Account#:

Procedures for payment

LHAs:

1. Complete the independent contractor form. Here is the information
    Client= The PI
    IC= your name
    Your tax identification number= your social security number

    1. Perform in-person tailored home visits
    2. Provide tailored home visit session and contact information to project office
    3. Client provides all documents
    7. This agreement shall end on August 30, 2009…10 days prior written notice

2. The terms should be $50 per completed interview, with data transfer to Project manager. This payment includes mileage, anything that you purchase on your own for your participant (e.g., meals or drinks), and anything else.

3. Please do not go to any personal expense for this project. If you need to buy something, check with the Project manager first.

4. Complete the W-9 form.

5. After you have done 5 home visits, please send the Project Manager an invoice.

6. You should receive a check in 4-6 weeks or sooner. If you haven't, check with the Project manager.

Participants:

1. After they complete the survey/interview, please have them fill out (or you fill out) the research subject payment form. Do a separate one for each person.

2. If they are not comfortable filling out the form, we cannot provide the check. Please let them know that they will receive a gift instead if they wish, take down the name, and talk this over with the Project Manager.

3. Please encourage them to take the check option. If they are reluctant, you might even suggest that they donate the money. Remind them that you are not paying for this!

4. Remind them that every time they participate in this program, they will receive a check.