Informed Consent to Take Part in a Research Evaluation

Title: Empowering Latinas to Obtain Breast Cancer Screenings
Principal Investigator: Yamile Molina, PhD

The study is being conducted collaboratively between Centro Comunitario Juan Diego, The Resurrection Project and the University of Illinois at Chicago's School of Public Health. This research is designed to provide major contributions to the science of cancer health equity. Specifically, we are comparing the effectiveness of two types of interventions to improve the breast health of Latinas living in Chicago, IL. One intervention focuses on giving Latinas breast health education. The other intervention focuses on giving Latinas an opportunity to learn not only breast health information, but also information on how to talk to family and friends about breast health as well as volunteer in breast health activities. We are asking you to take part in this research so that we may better understand how to best meet the needs of the Latina women in terms of breast health education.

Why is this research being done?

The purpose of this study is to understand and compare breast health interventions' effects on women's behaviors and social networks. You have been asked to participate in the research because you have met the following criteria for this research study. You

- Are between 52-75 years old;
- Identify as a Latina/Hispanic/Chicana woman;
- Live in Pilsen, Little Village, East Side or South Chicago;
- Have no history of health volunteerism;
- Have no history of breast cancer; and
- Have not obtained a mammogram within the last two years.

Your participation in this research is voluntary. Your decision whether or not to participate will not affect your current or future dealings with Centro Comunitario Juan Diego, the Resurrection Project or the University of Illinois at Chicago. Your decision whether or not to participate will also not affect your current or future dealings with any family member or friend who may have told you about this study. If you decide to participate, you are free to withdraw at any time without affecting that relationship.

How many people will take part in this research?

150 Latina women will take part in this program. All 150 of these women will be like you. Each workshop will include 3 educational sessions across 3 weeks and will likely include 6 to 8 participants.

Study Procedures

Each workshop will take place across three sessions within three weeks and will be a group of 6-8 Latina women. We will recruit 75 women from the Pilsen/Little Village and 75 women from the East Side/South Chicago. We will continue conducting workshops until 150 women have participated. UIC staff will be present at all study activities. The UIC staff are fully bilingual in Spanish and English. You will be assigned to the group

you selected during recruitment, either a Spanish language only workshop or an English language only workshop. Your signature will be required on this Informed Consent form.

Each workshop will have three educational sessions that should take about two to three (2-3) hours. During this first session, the UIC staff will first give an overview about the sessions/workshops, including our research questions and the outcomes we hope to address. Next, we will ask for your help with a questionnaire, which will include a random 6-digit identification code and will not be linked to your name or contact information. Community Health workers will present then the educational session. We will meet and give two other presentations across the next two weeks. After the third session, we will ask for your help with another survey. Across the next six months, you will be called monthly on the phone by UIC study staff to see how you are doing. Finally, we will ask for your help with a third questionnaire six months after the last session.

During the workshops, we will ask you to give us a name to identify you. This name can be anything you like and may not need to be your legal or given name. You can also choose to not use a name. Regardless, we will not use your name during any notes that are taken. After the workshops, all forms will be scanned, stored and kept by the Principal Investigator in a password-protected computer in a locked office.

If you choose to participate in this project, you have the right to withdraw at any point in time. You also have the right to refuse to answer any questions you wish to not answer.

If you would like, our study team can also store your contact information (specifically your name and phone number) to alert you about other future research studies. Only members of this study team would have access to your information and only they would contact you with information about the new study. When contacted, you would not be obligated to participate in this other research and it would not affect the relationships you have with this study team, Centro Comunitario Juan Diego, The Resurrection Project, or the University of Illinois at Chicago. If you were however interested, the study team would then give you the information you would need to begin related activities for those studies, including the consenting process. At that point in time, as well, you would be able to let us know if you do not want to be contacted again. We would then remove your name and phone number from our records.

☐ **I agree** to allow the researchers to contact me about future research. Initials _____.

☐ **I do not agree** to allow the researchers to contact me about future research. Initials _____.

Written Questionnaires

You will be asked to complete three surveys: 1 at the first session, 1 at the third session, and 1 six months after the workshops. All information will be anonymous (without linking your name or identity). We are not collecting any personal information at these sessions that could identify you. Survey 1 will include information about demographics (years in US, country of birth, income, education, marital status, age), volunteerism history, social interactions, breast cancer beliefs (cultural beliefs, perceived risks, norms and social interactions concerning breast cancer) and breast cancer screening variables. Survey 2 collect information related to volunteerism history, social interactions, breast cancer beliefs (cultural beliefs, perceived risks, norms and social interactions concerning breast cancer) and breast cancer screening since Survey 1. Survey 3 will collect information related to collect information related to volunteerism history, social interactions, breast cancer beliefs (cultural beliefs, perceived risks, norms and social interactions concerning breast cancer) and breast cancer screening since Survey 1.

You do not have to answer any questions that make you uneasy. We will keep the electronic copies of the questionnaires in a password-protected computer in a locked office to protect your privacy.

If you choose to participate in this project, you have the right to withdraw at any time. You also have the right not to answer any questions in the group.

How long will you be in the research?

The study will involve three 2 hour sessions across 3 consecutive weeks for each participant and a final survey, which should take about 20-30 minutes. The sessions will be closed group format so that once you decide to enroll into a particular group of sessions, you will be required to attend the 3 sessions consecutively for the three weeks for that group. You may not switch to another group. You will be given the dates, times and location once you have decided to participate and have selected a group at time of recruitment.

If you choose to recruit your friends and family, you will be given coupons with unique numbers. At the end of the study, we will communicate with you about compensating you for your time and effort in recruiting your friends and family. If you would like to receive your compensation by mail, we will obtain the address you prefer. If you would like to receive your compensation in person, we will ask you to come to UIC School of Public Health.

Can you stop being in the research?
Yes. You can decide to stop or not take part in the research at any time.

What risks can you expect from being in the research?
Taking part in this research does not involve any physical risk to you. You may feel uncomfortable talking about some of the questions. A risk of this research is a loss of privacy (revealing to others that you are taking part in this study) or confidentiality (revealing information about you to others to whom you have not given permission to see this information).Please feel free to not answer or withdraw from participating, if you feel uncomfortable answering any questions or with the discussion.

Are there benefits to taking part in the research?
You will not get any health benefit from taking part in this study.

What about privacy and confidentiality?
The only people who will know that you are participating in research will be the Principal Investigator, study staff from UIC and the other participants in the educational session and workshops. Although we ask everyone in the group to respect everyone's privacy and confidentiality, and not to identify anyone in the group or repeat what is said during the group discussion, please remember that other participants in the group may accidentally disclose what was said. Some of the participants in the group session may know you and, although we will ask everyone not to repeat what is said in the group, this cannot be guaranteed.

No information about you or provided by you during the research will be disclosed to others without your written permission except if necessary to protect your rights or welfare (or when the UIC Institutional Review Board monitors the research or consent process) or if required by law. Information collected at the group session will be kept separate from confidential information, such as our Call Log we used during Recruitment and this informed consent form. Your collected survey will have no names and cannot be traced back to you. Your answers during the workshops will not be associated with your name or any other parts of your information. The de-identified data will be stored at the Principal Investigator's office at the University of Illinois at Chicago's School of Public Health. All information will be kept in a locked file and stored on a secured computer that is password protected. Any reports or publications about this study will not include your names. The University of Illinois at Chicago, Institutional Review Board and the Illinois State Auditors may also monitor the research.

If you have any questions about your rights as a research subject, you may call the University of Illinois at Chicago, Office for Protection of Research Subjects at 312-996-1711.

What are the costs?
There will be no cost for you to take part in this research.

Will you be compensated?
You will be compensated for your time with $80 in cash ($10 during Session 1; $20 during Session 2; $25 during Session 3; $25 during Survey 3). If you choose to recruit family and friends to participate, we will

provide you with some cash to compensate you for your efforts. We will also offer snacks during or after the group.

What are your rights if you take part in this research?
Taking part in these group sessions is your choice. You may choose either to take part or not to take part in the workshops. If you decide to take part in this research study, you may leave it at any time during the workshops.

Who can answer your questions about the research?
If you have any questions about this study or if you have a concern or complaint, please call:

Yamile Molina, PhD
University of Illinois at Chicago
Phone: 312-355-2679
Email: ymolin2@uic.edu

By signing below, you tell us that you have gotten all of the information you need; that you have received clear answers to your questions, and that you agree to take part in the research. You will get a copy of this form. You may also ask for a copy of the research plan.

Signature of Participant **Date**

Signature of Person Obtaining Consent, Degree **Date**

By signing this form the person obtaining consent indicates that the research study participant has been fully informed of all aspects of the research.