

# MUSLIM AMERICANS REACHING FOR HEALTH AND BUILDING ALLIANCES



MARHABA  
CONSULTANT  
TRAINING

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# INTRODUCTIONS

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# MARHABA Academic Partners

## MARHABA Project Team

- Nadia Islam - Principal Investigator
- Shilpa Patel - Program Manager
- Nassira Bougrab - Coordinator
- Gulnahr Alam - Community Health Worker

## Additional team members

- Dr. Victoria Raveis - Colleges of Dentistry & Nursing, NYUMC
- Dr. Simona Kwon - Department of Population Health, NYUMC
- Dr. Annette Maxwell - UCLA Fielding School of Public Health
- Dr. Joseph Ravenell - Department of Population Health, NYUMC
- Dr. Shubhada Dhage - NYU Perlmutter Cancer Center
- New York State Department of Health

# MARHABA Community Partners

Organization	Muslim Ethnic Groups Served				
	African American	African	Middle Eastern	South Asian	SE Asian
Adhunika				X	
Al-Hikmah Masjid					X
At-Taqwa Masjid	X		X	X	
American-Italian Cancer Foundation	X	X	X	X	X
APartnership			X	X	X
Arab American Family Support Center			X	X	
Astoria Islamic Center			X	X	X
Baitul Mamur Masjid and Community Center	X	X		X	
Bangladeshi American Community Development & Youth Services (BACDYS)	X			X	
Bangladesh Muslim Center				X	
Bellevue Hospital	X	X	X	X	X
DREAM Coalition				X	
HealthLink	X	X	X	X	X
India Home				X	
Jamaica Muslim Center				X	X
Madina Masjid	X	X	X	X	X
NYU Muslim Students Association	X	X	X	X	X
Masjid Aqsa	X	X			
South Asian Council for Social Services (SACSS)				X	
Turning Point for Women and Families			X	X	
Women Conquering Cancer	X	X	X	X	
Yankasa	X				

# BACKGROUND ON MUSLIMS IN THE U.S.

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## Muslims in the U.S.

**Globally, Muslims are one of the fastest growing religious groups**

- NYC is home to the largest and most diverse concentration of Muslims in the U.S.
- There are more than 100 mosques and 600,000 Muslims in NYC; about 276,000 of the Muslims in NYC are female

## Breast and Cervical Cancer Screening

**Muslim women may have lower rates of breast and cervical cancer screening and higher rates of developing these cancers compared to the overall population**

- ~33% have never had a mammogram
- 16-50% have ever had a Pap

**Women from Muslim countries have higher rates of dying from breast and cervical cancer compared to women from other countries**

## MARHABA Goal

To increase breast and  
cervical cancer screening  
among Muslim women  
in the five boroughs of  
New York City – Queens,  
Manhattan, Brooklyn, Bronx,  
and Staten Island

## REVIEW OF MARHABA I

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# MARHABA I Goals

1. To build a coalition of academic, clinical, and community partners to start a breast and cervical cancer research project among the Muslim population in NYC
2. To study what helps and what prevents women from getting breast and cervical cancer screening
  - Attitudes, beliefs, family, friends, insurance, knowledge
3. To create a health campaign to increase knowledge about breast and cervical cancer screening

# MARHABA I Methods



4	<u>Community Health Workers</u> <ul style="list-style-type: none"> <li>• Gulnahar Alam</li> <li>• Ramatu Ahmed</li> <li>• Potri Rankamanis</li> <li>• Rosa Hudson</li> </ul>
15	<u>Community partners</u> <ul style="list-style-type: none"> <li>• Mosques</li> <li>• Community-based organizations</li> <li>• Student organizations</li> </ul>
12	<u>Community leader interviews</u> <ul style="list-style-type: none"> <li>• Imams</li> <li>• Health providers</li> <li>• Community leaders</li> </ul>
98	<u>Interviews with women in the community</u> <ul style="list-style-type: none"> <li>• Asked questions about cancer, screening, health care experiences</li> <li>• African-American, African immigrant, South Asian, Middle Eastern, South East Asian</li> </ul>
37	<u>Focus groups with women in the community</u> <ul style="list-style-type: none"> <li>• Asked questions about health campaign</li> </ul>



# MARHABA I Results

## What prevents women from getting breast and cervical cancer screening:

- Lack of female doctors and other healthcare providers
- Lack of translated materials
- Lack of knowledge about cancer
- Fear, stigma, modesty
- Different between older vs younger women

## Recommendations for increasing screening:

- Education
- Translated materials and messaging
- Work with mosques and religious leaders

# MARHABA II

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# MARHABA II Project

The project will compare two groups of women:

## GROUP A

Women will receive all MARHABA materials and will attend a one hour educational session

## GROUP B

Women will receive all MARHABA materials, attend a one hour educational session, and get additional help from you with their screening appointment

We will look for changes in:

1. Number of women who get a mammogram and/or Pap test
2. Change in knowledge about breast cancer, cervical cancer, mammograms, and Pap tests

# MARHABA II Project

All participants will:

- Attend a 1-hour educational seminar on BC and CC screening
- Receive MARHABA materials

## GROUP A

- No additional contact from consultant
- Encouraged during seminar to schedule mammogram and/or Pap test or refer to webpage for information

## GROUP B

- Three planned contacts with consultants that focus on navigation for obtaining mammogram and/or Pap
- Potential for additional 3 brief reminder/follow-up contacts from consultants

All participants who receive an abnormal mammogram or Pap will be invited to consult at NYU Cancer Center and discuss options for follow-up

# MARHABA II: Who can participate

CAN Participate	CANNOT Participate
<ul style="list-style-type: none"><li>✔ Muslim</li><li>✔ Female</li><li>✔ 40-75 years</li><li>✔ Live in 5 boros of NYC</li></ul>	<ul style="list-style-type: none"><li>✘ Do not meet criteria on left</li></ul>
AND	OR
<ul style="list-style-type: none"><li>✔ Did not get a mammogram in the last 2 years (Ages 40-74)</li></ul>	<ul style="list-style-type: none"><li>✘ Had breast or cervical cancer before</li></ul>
OR	
<ul style="list-style-type: none"><li>✔ Did not get a Pap test in the last 2 years (Ages 40-64)</li></ul>	<ul style="list-style-type: none"><li>✘ Had breast reconstructive surgery</li></ul>

## MARHABA II PROCESS

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## Where will women come from?

### Community-based events and locations:

- Health Fairs & Seminars
- Religious Education Classes

### Mosques:

- Announcements during Friday Jummah prayer
- Women's Weekly Halaquah

### Other:

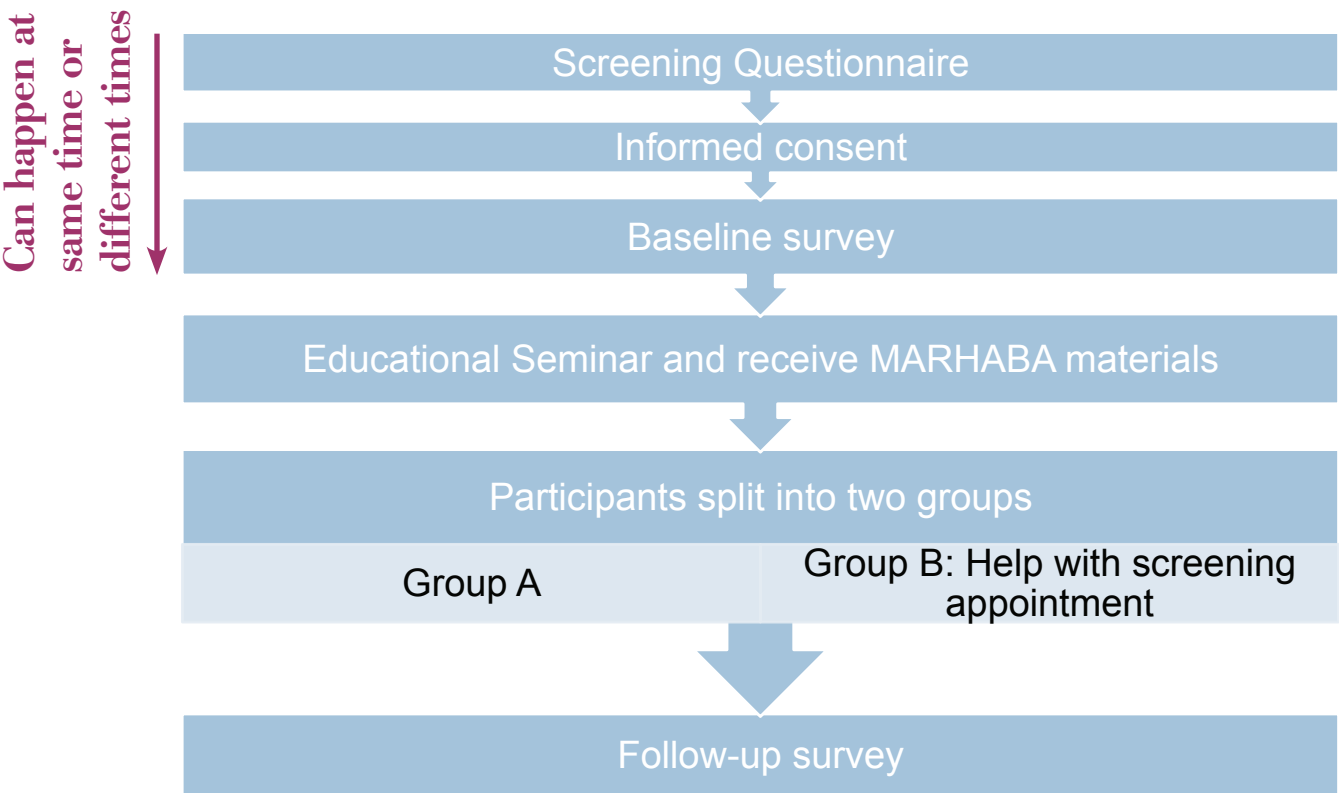
- Networks: Family, friends, etc.

\* Use the Informational Sign-Up Sheet to collect information

## How do I get women to participate?

- Use your **connections** from the community
- **Be honest and respectful**
- **Be open and non-judgmental**
- **Be persistent and resourceful**
- **DON'T** take it personally if women do not want to participate in the project or are not interested in the information

# MARHABA II Project Process



All participants who receive an abnormal mammogram or Pap will be invited to consult at NYU Cancer Center and discuss options for follow-up

# PARTICIPANT ENGAGEMENT

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## Participant Engagement

### Some talking points:

- The project received money from the government, specifically the Centers for Disease Control and Prevention (CDC), but no one will profit from the project. We just want to help Muslim women learn more about breast and cervical cancer.
- I am getting paid as part of the project as a consultant, but did not directly receive money from the government. NYU Medical Center received the money from the government.

## Information points to bring up during your conversations

“We will be giving you information about breast and cervical cancer and screening for a project from NYU Medical Center”

“None of your information will be shared with your providers, your job, your family, or friends”

“If you have any questions, please reach out to Nahar, Nassira, or Shilpa”

# SCREENING QUESTIONNAIRE

# Script

Script: “Hello, I am a team member of the MARHABA research project to study a program to help community members get breast and cervical cancer screening. I will ask you some questions to see if you are eligible to participate in this project, and if you are eligible, you will have the option to participate. I will explain the project and what you will be asked to do as part of the project, and you will have an opportunity to ask questions. If you decide to participate in the project, I will ask you to sign a consent form.”

Date: \_\_\_\_\_

## QUESTIONS TO ASSESS ELIGIBILITY:

1. Do you identify as Muslim?
  - a. No [IF NO, participant is not eligible. END THE SURVEY]
  - b. Yes
2. Are you female?
  - a. No [IF NO, participant is not eligible. END THE SURVEY]
  - b. Yes
3. Do you live in New York City?
  - a. No [IF NO, participant is not eligible. END THE SURVEY]
  - b. Yes
4. How old are you? \_\_\_\_\_ [IF AGE<40 OR >75, participant is not eligible. END THE SURVEY]
5. Have you ever been diagnosed with breast or cervical cancer?
  - a. No
  - b. Yes [IF YES, participant is not eligible. END THE SURVEY]
6. Have you ever had breast reconstructive surgery?
  - a. No
  - b. Yes [IF YES, participant is not eligible. END THE SURVEY]
7. Are you pregnant?
  - a. No
  - b. Yes [IF YES, participant is not eligible. END THE SURVEY]
8. Have you ever had a hysterectomy?
  - a. No [IF NO, go to Question 9.]
  - b. Yes [IF YES, do not ask Question 10. Participant only eligible if NO to Q9.]

## For Women Age 40-74

9. Have you received a mammogram in the last two years?
  - a. No
  - b. Yes

## For women Age 40-64

10. Have you received a Pap smear in the last three years?
  - a. No
  - b. Yes

[IF YES TO QUESTIONS 9 AND 10, PARTICIPANT IS NOT ELIGIBLE. END THE SURVEY]

# INFORMED CONSENT

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# Consent to Participate in a research study



## Research Subject Informed Consent Form

Title of Study: Muslim Americans Reaching for Health and Building Alliances (MARHABA): Lay Health Worker Intervention to increase breast and cervical cancer screening among Muslim women in New York City

Version date: August 2, 2016

Principal Investigator: Nadia Islam, PhD  
Department of Population Health, NYU Medical Center, 227 East 30<sup>th</sup> Street, 8<sup>th</sup> Floor, NY, NY 10016; 212-263-7075

Emergency Contact: Shilpa Patel  
Department of Population Health, NYU Medical Center, 227 East 30<sup>th</sup> Street, 8<sup>th</sup> Floor, NY, NY 10016; 646-501-2743

**1. About volunteering for this research study**  
You are being invited to take part in a research study. Your participation is voluntary which means you can choose whether or not you want to take part in this study. People who agree to take part in research studies are called "subjects" or "research subjects". These words are used throughout this consent form. Before you can make your decision, you will need to know what the study is about, the possible risks and benefits of being in this study, and what you will have to do in this study. You may also decide to discuss this study and this form with you have any questions at please ask us. If you decide sign this form. We will give you for you to keep.

**2. What is the purpose**  
The purpose of this study culturally adapted lay health worker intervention to increase breast and cervical cancer screening. The program, trained LHW will provide cervical cancer and will help screened. You are being asked to be Muslim female between the ages of 18 and 64.

We will ask you questions to determine if you are eligible to participate in this study. If you are eligible, then a member of the study team will explain the study and give you an opportunity to ask read through this form, ask questions and decide if you want to participate. As part of this study, we will ask you to complete a survey when you enroll into the program and another survey 4 months later. Surveys will last about 45 minutes and will ask you questions about breast and cervical cancer screening, health access and barriers to receiving care. You will receive information about your how and where to get a screening for breast and cervical cancer and you will receive a referral to doctor if you need it.

**5. What are the possible risks or discomforts?**  
**Risk of Study**  
There are minimal risks associated with participation in this study. A potential risk is the possibility for breaches in confidentiality. Every effort will be made to ensure participant confidentiality. However, absolute confidentiality cannot be guaranteed. Questions may be posed to subjects that are of a sensitive nature. The study may also involve risks that are currently unforeseeable.  
**Other Risks**  
There are no other risks involved in this study.

**6. What if new information becomes available?**  
During the course of this study we may find more information that could be important to you. This includes information that might cause you to change your mind about being in the study. We will notify you as soon as possible if such information becomes available.

**7. What are the possible benefits of the study?**

**12. When is the study over? Can I leave the Study before it ends?**

This study is expected to end after all participants have completed both surveys, and all information has been collected. If you decide to participate, you are free to leave the study at anytime. Leaving the study will not interfere with your interaction with the FBO or CBO in any way.

**13. How will my information be protected?**  
NYU Langone Medical Center, which includes NYU Hospitals Center and NYU School of Medicine, is committed to protecting the privacy and confidentiality of your health information. We are asking for your permission to use and to disclose your health information in connection with this study. You have the right not to give us this permission, in which case you will not be able to participate in this study. If you do not give this permission, your treatment outside of this study, payment for your health care, and your health care benefits will not be affected.

**What information about me may be used or shared with others?**  
The following information may be used or shared in connection with this research:

- Information in your research record, for example, results from your surveys.
- You have a right to access information in your research record. In some cases when necessary to protect the integrity of the research, you will not be allowed to see or copy certain information relating to the study while the study is in progress, but you will have the right to see and copy the information once the study is over in accordance with NYU Langone Medical Center policies and applicable law.

Consent to Participate in a Research Study NYU School of Medicine IRB HRPP Version: August 2, 2016

## Consent to Participate in a Research Study

Study Title	Muslim Americans Reaching for Health and Building Alliances (MARHABA): Lay Health Worker Intervention to increase breast and cervical cancer screening among Muslim women in New York City
Principal Investigator	Nadia Islam, PhD
Sponsor Name	Centers for Disease Control and Prevention
IRB Approval Period	
Research number	s16-00803

You are being invited to take part in a research study. Your participation is voluntary which means you can choose whether or not you want to take part in this study.

I ☐ have ☐ have not received and read the accompanying "Research Subject Informed Consent Form (Brochure)"

Continue Below **ONLY** if you received and read the brochure.

### Optional permission for future use

NYULMC would also like to store, use, and share your health information from this study in research databases or registries for future research conducted by NYULMC or its research partners. To give this additional permission, check the box below and write your initials where indicated. You may still participate in this study even if you do not give us this additional permission.

NYULMC will continue to protect the confidentiality and privacy of this information as required by law and our institutional policies. If you give this additional permission, you will continue to have the rights described in this form. You have the right to take back this additional permission at any time.

Gives participants information about the project

# What to sign for the Informed Consent

When you sign this form, you are agreeing to take part in this research study as described to you. This means that you have read the consent form, your questions have been answered, and you have decided to volunteer.

Name of Subject (Print)

Signature of Subject

Date

Name of Person Obtaining Consent (Print)

Signature of Person Obtaining Consent

Date

Page 1: Participant signs and dates the form here

Page 1: NYU staff signs here

## Witness to Consent of Non-English Speaking Subjects Using the "Short Form" in Subject's Spoken Language

### Statement of Witness

As someone who understands both English and the language spoken by the subject, I represent that the English version of the consent form was presented orally to the subject in the subject's own language, and that the subject was given the opportunity to ask questions.

Name of Witness (Print)

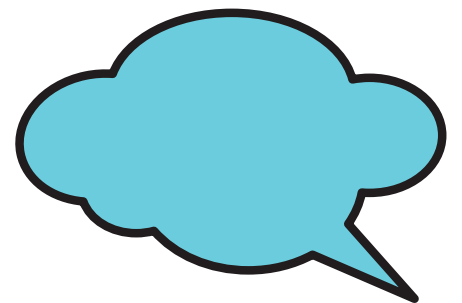
Signature of Witness

Date

Page 2: MARHABA consultant signs and dates the form here

## Group Activity : Obtaining Consent

- Now let's take time to practice with each other...
- For the next 15-20 minutes, work with your partner to review the consent brochure and complete the consent signature page



## BASELINE SURVEY

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## Baseline survey

- In-person or over the phone at participant's convenience
- In-language
- About 45 minutes long
- All women will get an incentive (gift card) for taking the survey
- Different types of information
- Participant information, health information, beliefs about breast and cervical cancer, breast and cervical cancer knowledge

## Before the Survey...

- Consultants's role
- Meeting the participant
- Establishing a relationship with the participant
- Utilize welcome script to schedule the baseline survey

## Consultant's Role

- Gather information
- How do people feel and think about certain things?
- NOT change or influence the participant

## Meeting the participant

- Make sure you are familiar with survey, especially if doing the survey in another language
- Introduce yourself and why you are doing the survey
- First impression can have significant impact on relationship with participant
  - Dress appropriately
  - Establish a quiet, safe place for interview
  - Ability to adapt to situation

## Establishing a relationship

- Be warm and responsive to participant
- Keep a pressure-free atmosphere
- Make sure the participant knows information is confidential
- Be sensitive to participant's needs and limitations
- Keep a positive atmosphere
- No right or wrong answer
- Be aware that some questions may be sensitive and some people may want to explain their answers or not answer questions

## During the Survey...

- DON'T ask personal questions that are not on the survey or discuss the information from the interview with others
- DON'T take it personally if people have to stop the interview or don't want to participate in the project anymore
- DO allow the person to "skip" a question if they don't feel comfortable answering
- DO share with them that their information will be kept private



## During the Survey...

- Ask all questions on the survey and in order
- Read all responses first, and then ask participant to respond to question
- If question is “Check all that apply,” make sure that participant knows they can choose more than one response
- Participant can also choose Don’t know or Refused as a response
- Write legibly and clearly mark answer
- If you don’t understand a question or the responses, ask!

## After the Survey...

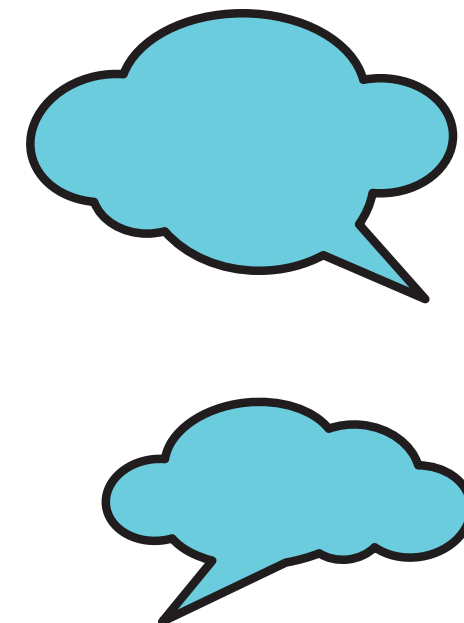
- As a consultant, you have to protect the participant’s privacy and personal information
- Please do not share this information with anyone, including your own family and friends
- Do not keep information with personal information out where other people can see it
- Refer back to welcome script to schedule educational seminar
  - You can use the reminder script for 1-2 days before the seminar

## Things that could happen during the survey

- Participant needs to reschedule
- Interview site no longer available
  - Be flexible – as long as it's a quiet, semi-private space, you can conduct interview
- Participant cannot finish the interview
  - Make another in-person or phone appointment
- Participant does not stay on topic or gets distracted
  - Try to bring participant back to survey but if too busy, make another appointment

## Group Activity: Mock interviewing

- Now let's take time to practice with each other...
- For the next 15-20 minutes, work with your partner to do a “mock” interview



# EDUCATION SEMINAR

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## Goals of Seminar

- Gain trust and build relationship with participants
- Get to know the participants, especially their thoughts about mammograms and Pap tests
- Learn about their mammogram and Pap test history
- Educate participants about breast cancer, cervical cancer, and importance of mammogram and Pap tests
- Encourage participants to get mammograms and Pap tests

## Ground Rules

- You choose how much you share with the group
- We respect confidentiality
- We don't discuss medical advice – see your doctor
- We don't have all of the answers – we are all here to learn
- Time is limited

## How to Lead a Group Discussion

- Create a comfortable environment that encourages all points of view and allows everyone to speak
- Encourage participation in the discussion
- Make sure participants feel heard and respected
- Provide information covered in training, but remember you are not a doctor, so please do not give medical advice

## Supportive Communication

- It is important to help women feel comfortable talking about breast and cervical cancer.
- Things we can do to help women feel safe:
  - Make eye contact
  - Use “open” body language like leaning forward when listening and leaving arms open (not crossed)
  - Speak gently and slowly
  - Pause and give her time to think about what she wants to say
  - Tell her that you respect her feelings
  - Encourage talk with simple phrases like “yes” and “OK”

# GROUP B: ADDITIONAL CONTACTS

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Three Additional contacts

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## Three Additional contacts

### Group B participants

- Follow-up phone calls
- Help with making and getting to appointments as needed

#### First contact

- After baseline survey+educational seminar
- Focus:
  - Help participants make an appointment
  - How to get a low-cost or free screening if needed

#### Second contact

- After baseline survey+educational seminar+scheduled appt
- Focus: Process when participant goes to appointment
- Note: Participant may want you to go to appt with them

#### Third contact

- After baseline survey+educational seminar+completed appt
- Focus: Obtaining or reading results

## FOLLOW-UP SURVEY

## Follow-up survey

- Similar to baseline survey
- Takes out participant information
- Additional questions on:
  - Breast and cervical cancer screening appointment
  - Satisfaction and experience with project
    - MARHABA materials
    - Educational seminar
    - Consultants

## CONSULTANT EXPECTATIONS

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## Consultant Expectations: Administrative

- Complete all NYU Medical Center forms and interviews to become consultant
- Attend at least 9 hours of MARHABA consultant trainings
- Pass all competency exams related to trainings
- Report to project supervisors via email or phone every other week
- Participate in meeting with other MARHABA consultants every other month by conference call or in-person meetings

## Consultant Expectations: Project

### Outreach

- Talk to Muslim women about the project
- Get about 5-20 Muslim women per month to sign up for the project
- Keep participants engaged and enthusiastic
- Educational seminars
- Assist with translation and review of materials

### For Group B participants

- Assist with appointments
- Additional education, counseling and support if needed

## What is due to Shilpa & Nahar

- Screening form
- Consent form
- Baseline survey
- Follow-up survey
- Informational Sign-up sheets
- Additional forms

## Additional Forms

- **Number of**
  - Educational seminars
  - Women who attended educational seminars
  - Women who enroll into MARHABA project
  - Women who complete MARHABA project
  - Incentives given out
- **Information on navigation calls made (and notes on each call)**

# QUESTIONS



# PART 2

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## Who is at risk for cancer?

- Many women think White women mostly get cancer and it is rare among Muslim women
- But cancer rates are increasing among Muslim women who live in the U.S.
- The longer you live in the U.S., the higher your risk of cancer
- The risk of cancer also increases as you get older
- Every woman is at risk for breast and cervical cancer
- Over 90% of the people with cancer do not have symptoms
- Screening helps catch cancer early before it becomes difficult to treat

## What is a cancer screening test?

- A cancer screening test looks for signs of cancer in a person who does not have any symptoms of the disease
- Breast cancer
  - Mammogram
- Cervical cancer
  - Pap test – looks for changes in cells that could become cancer
  - HPV test – looks for virus that can cause the changes in the cells

## Common myths about cancer

- I don't need a cancer screening test if I don't have any symptoms
  - A screening can find cancers early, before a doctor can see it or feel a lump
- I will die if I get cancer
  - If cancer is found at very early stages, it can be successfully treated
  - But it has to be caught early. If it is caught too late and is big, it can cause more damage or require more treatment

## BREAST CANCER

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## Breast cancer

- Breast cancer (BC) is the most common cancer among women in the U.S. and the world
- BC is the second leading cause of cancer death among American women
- In the U.S., 1 in 8 will develop breast cancer



## What are the risk factors for breast cancer?

**Your risk for breast cancer goes up as you get older.**

- 2/3 of cases occur in women over 50 years

**Other things that could increase your risk:**

- Family history of cancer
- Never had children
- First child after age 30
- Began menstruation before age 12
- Began menopause after age 55
- Drink alcohol
- Obese or overweight

*Not having any of the above risk factors does NOT mean that you are “safe”*

## What are the warning signs of BC?

- Most common sign – lump or thickening in breast
- Change in size or shape of breast or breast discharge from nipple
- Change in color (especially redness that does not go away) or texture of skin of breast or skin around nipple
- However, often there are no signs of BC until the disease has progressed into advanced stages

*A mammogram can detect BC before it can be felt or seen*

## What is a mammogram?

- A mammogram is an X-ray picture of the breasts.
- X-rays can find breast cancer that is too small for you or your doctor to feel. When breast cancer is found early, it is easier to treat.
- A mammogram can find cancer up to 2 years before a lump can be felt.



## How is a mammogram done?



1. You are given a gown to wear for the test
2. You will stand in front of an X-ray machine
3. The person who is doing the mammogram will gently place your breast between two plastic plates, which will make your breast flat and may feel uncomfortable for a few minutes
4. Results are discussed with your health care provider at a follow-up appointment or via phone call

## What if the mammogram finds a lump?

- Most lumps are not cancer. Your doctor will help decide if you need more tests.
- If cancer is found and treated early, most women can be cured.
- In many cases, only the small lump will need to be taken out, saving the breast.

## What if the mammogram is abnormal?

There are multiple reasons a mammogram can look abnormal and not all things they find during a mammogram are cancer

If there is an abnormality:

- The person may need another mammogram in 6 months
- The person may need a biopsy
  - The standard method of biopsy is an image guided biopsy
  - **SURGICAL BIOPSY IS NOT THE STANDARD OF CARE**

## When should I get a mammogram?

If you are...	You should ...
Between the ages of 40 and 49 years *	Talk to your doctor about when and how often you should start getting a mammogram
Between the ages of 50 – 74 years	Get a mammogram every two years
75 years and over	Talk to your doctor about when and how often you should get a mammogram

\*Some immigrant Muslim women may get cancer at younger ages, so please talk to your provider about what age is right for you



## Breast cancer treatment options

**Surgery – Depends on stage and prognosis of cancer**

- Lumpectomy - Removal of lump
- Mastectomy - Removal of entire breast if cancer in different parts of the breast
- Removal or biopsy of lymph nodes in arm pit region

**Radiation therapy – High energy rays are used to damage the cancer cells and keep them from growing**

- Sometimes from machine or placed directly in breast

**Chemotherapy – Use drugs through needle to kill cancer cells**

**Targeted therapy – Focus on specific parts of the cancer cells**

**Hormone therapy – Used to make sure cancer cells don't get the hormones they need to grow**

- Could be drugs or surgery (e.g. remove ovaries, which make hormones in the body)

## Common mistakes about a mammogram & BC

**Only women with large breasts get breast cancer**

- There is no relationship between breast size and cancer

**Only women with dense breasts get cancer**

- Density is related to cancer risk, however any woman can get cancer

**If I had one normal mammogram, I don't need another one**

- If you had one mammogram, that's a terrific start. But once is not enough. If you are between 50-74 years, you should get a mammogram every two years. If you are between 40-49 years or over 75 years, you should talk to your doctor about the risks and benefits of getting a mammogram.



# CERVICAL CANCER

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## Cervical cancer

- Cervical cancer (CC) is the 4th most commonly diagnosed cancer in the world
- CC is the 4th leading cause of cancer death in the world
- CC is very preventable - 99% curable if discovered very early

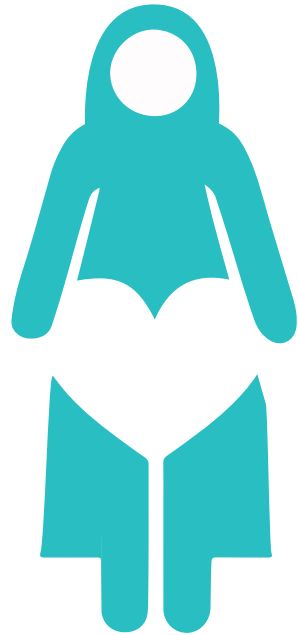


## What are risk factors for cervical cancer?

- Human papillomavirus infection – viral infection passed between people, usually sexual contact
- Smoking
- Diet low in fruits and vegetables
- Overweight
- Long term use of birth control pills
- 3 or more full term pregnancies
- Younger than 17 years at first full-term pregnancy
- Family history of cervical cancer
- ALL women are at risk for cervical cancer

## What is a Pap test?

- A Pap test (or smear) is part of the pelvic exam done at the doctor's office
- It is used to examine samples of your cervix and vagina to check for signs of infection and cancer
- It is the best way to be sure you don't have cancer in your cervix or vagina
- If the cancer is caught early, it can usually be treated with success



## Why is a Pap test important?

- It is possible to prevent or cure cervical cancer by removing the abnormal cells before they become cancer
- Cervical cancer does not have any symptoms when abnormal cells turn into cancer cells so it is important to have Pap tests done regularly

## How is a Pap test done?



1. You are given a gown to wear for the test.
2. You will lie on an exam table with your feet in stirrups.
3. Your health care provider will gently open your vagina.
4. Samples are taken from your vagina and cervix.
5. Samples are sent to a lab for testing.
6. Results are discussed with your health care provider at a follow-up appointment or via phone call.

## What if the Pap test is abnormal?

- The doctor may ask for another Pap test
- They may do another test called a colposcopy which is like Pap, but they use a special microscope to examine the cervix

## When should I get a Pap test?

If you are...	You should...
At least 21 years old	Start to get regular Pap tests every three years
Between the ages of 30 – 65 years	Get a Pap test every three years OR Every 5 years if you combine the Pap test with a test for HPV infection
Older than 65 years	Talk to your doctor about when and how often you should get a Pap test

## Treatments for CC

- Cryotherapy – destroys the abnormal cells by freezing them
- Carbon dioxide laser cautery – beam of light burns the abnormal cells
- Cone biopsy – minor surgery which removes the abnormal tissue
- First two treatments take less than 5 minutes and all treatments are simple, almost always cure the abnormal cells, and should not affect fertility or future child-bearing

# Common mistakes about a Pap test

## A Pap test affects your virginity

- A Pap test does not affect your virginity

## You only need to get a Pap if you are sexually active or are still getting your period

- Risk of cancer increases as you get older

## You do not need to get a Pap if you had a hysterectomy

- You should talk to your doctor about getting a Pap even if you had a hysterectomy

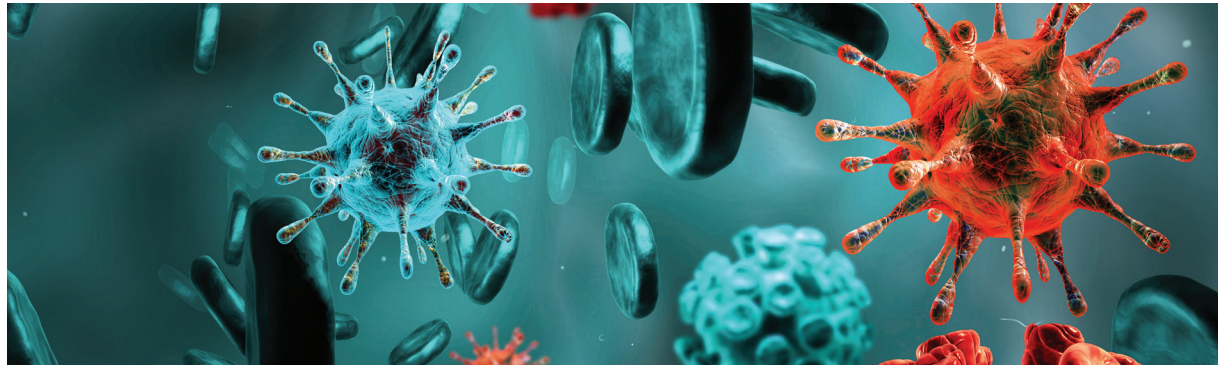
## HPV

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## What is HPV?



- HPV is short for human papillomavirus
- HPV is a group of more than 150 related viruses. HPV is named for the warts (papillomas) some HPV types can cause
- Some other HPV types can lead to cancer, especially cervical cancer
- There are more than 40 HPV types that can infect the genital areas of males and females. But there are vaccines that can prevent infection with the most common types of HPV

## How do people get HPV?

- HPV is transmitted through intimate skin-to-skin contact. You can get HPV by having vaginal, anal, or oral sex with someone who has the virus. It is most commonly spread during vaginal or anal sex.
- HPV is the most common sexually transmitted infection (STI). Anyone who is sexually active can get HPV, even if you have had sex with only one person.
- HPV is so common that nearly all sexually active men and women get it at some point in their lives. HPV can be passed even when an infected person has no signs or symptoms. You can develop symptoms years after you have sex with someone who is infected, making it hard to know when you first became infected.

## HPV Vaccination

- The HPV vaccine is important because it protects against cancers caused by human papillomavirus (HPV) infection.
- HPV is a very common virus; nearly 80 million people—about one in four—are currently infected in the United States.
- Vaccination to protect against HPV is important.

## When should my child be vaccinated?

- The HPV vaccine is recommended for preteen boys and girls at age 11 or 12 so they are protected before ever being exposed to the virus.
- Finally, older teens are less likely to get health check-ups than preteens. If your teen hasn't gotten the vaccine yet, talk to their doctor or nurse about getting it for them as soon as possible.



## HPV Vaccine

The HPV vaccine is given in 3 shots.

The second shot is given 1 or 2 months after the first shot. Then a third shot is given 6 months after the first shot.

The CDC recommends receiving the full HPV vaccine series.

## HPV Vaccination



# WHAT CAN PREVENT AND WHAT CAN HELP WOMEN GET CANCER SCREENING?

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## What prevents women from getting cancer screening

- Cost
- Don't have time
- Don't have a way to get to the appointment
- Not recommended by my doctor
- No history of cancer in my family
- Fear of radiation
- Fear of finding cancer
- Pain
- Embarrassment

## What prevents women from getting screened

### Cost

- Places to get reduced price or free breast and cervical cancer screening and care if cancer is found

### Inconvenience

- Your health should be important to you and your family

## What prevents women from getting screened

### No history of cancer in my family

- 4 out of 5 women who get breast cancer have no family history

### Not recommended by my doctor

- Sometimes doctors focus on the reason for your visit and they forget to talk about regular screenings and tests
- It is your responsibility to ask your doctors about these tests to maintain your health

## What prevents women from getting screened: Pain

### Pain (mammogram)

- In order to get a good picture, the breast has to be compressed, which can be uncomfortable or even painful. However, this will only take a few seconds, and you could be saving your life and your family grief.

### Pain (Pap)

- In order to get enough material for the Pap test, the healthcare provider needs to insert an instrument into your vagina, which can be uncomfortable or even painful. However, this will only take a few seconds, and you could be saving your life and your family grief.

## What prevents women from getting screened: Embarrassment

### Embarrassment

You can always request a female doctor or technician. We must conquer the embarrassment if we care about our bodies and ourselves. Our health is very important – more than anything.

## What prevents women from getting screened: Fear

### Fear of radiation (mammogram)

- Very little radiation in mammogram – Half of what you get from dental x-rays and fraction of what you get from the environment naturally over one year

### Fear of finding cancer

- You may be nervous when you go for your screening test and concerned about finding cancer, but finding it early gives the best chance for treatment and survival
- Important to get screened regularly, even if you feel healthy

## What helps women get screened

### Religion

- Allah created human beings and gave them their bodies as gifts to be cared for

### Family

- In order to take care of your family, you must also take care of yourself

### Friends

- Information & education

## Group Activity: Role Playing

- Now let's take time to practice with each other...
- For the next 15-20 minutes, work with your partner to act out different scenarios and practice responding to barriers participants face – e.g. the woman is embarrassed, she doesn't think she needs to be screened, etc.



# ACCESS TO HEALTH CARE

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## Know your rights

- You have a right to go to a doctor, a clinic, an Emergency Room, a hospital, or call an ambulance, no matter what your immigration status is.
- All immigrants have the right to be treated if they have a medical emergency. Uninsured individuals and undocumented immigrants have the same rights to emergency care as all other New Yorkers.
- Anyone with a medical emergency has the right to an ambulance, regardless of immigration status or ability to pay. You can get an ambulance by calling 911.

## Know your rights

- You do not have to tell health workers what your immigration status is before receiving care.
- You do not need a Social Security Number (SSN) to receive emergency care or emergency medical transportation.
- You have the right to have information about your health care kept confidential, so it cannot be shared without your permission.
- Even if it is not an emergency, you can get care regardless of your immigration status or your ability to pay, in any public hospital.



## Obamacare\*

- On March 25, 2010, Congress passed the Health Care & Education Affordability Reconciliation Act of 2010 (HR 4872).
- This legislation makes improvements to the Patient Protection and Affordable Care Act (HR 3590) signed into law by President Obama days earlier.
- Both bills will increase access to care for nearly 32 million people.
- More people eligible for Medicaid
- Help people who were denied benefits because of pre-existing conditions before.

\*The American Health Care Act of 2017 is currently in the process of being signed into law. Until that happens Obamacare is still in place.

## Know your rights – Language

- Health care facilities throughout New York State are required by federal and state law to provide free language assistance to services for patients and family members who don't speak English well.
- Patients don't need to be U.S. citizens to have language access rights under American law.
- It is your right to be understood by hospital staff, and to understand what hospital staff is trying to communicate to you.

## Know your rights – Language

Who must comply with the language laws?

- Any hospital or clinic that receives Medicare or Medicaid
- Primary Care
- Acute and particularly emergency care

### ProLingua in Clinical Areas



Registration



\*Triage



Labs / Radiology



\*Diagnosis



Pharmacy



Floors / Nursing



Education



Discharge

\* areas where medically certified interpreter is needed

## Know your rights – Preventive services

Under new plan, people with private insurance and some types of public insurance now have access to more preventive services with no cost-sharing

- Well-child visits
- Blood pressure and cholesterol screenings
- Pap tests and mammograms

*For people without insurance, we have listed resources for women to get free or low-cost Pap tests and mammograms*



# RESOURCES FOR SCREENING

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American Cancer Society	119

## Cancer Services Program

### Free or reduced price mammogram and Pap tests for women in Queens

- 718-670-1561, Monday–Friday, 8am to 4pm
- <http://www.nyhq.org/Cancer-Services-Program>
- **CSP Borough Locations and phone numbers:**
  - **Bronx:** 718-579-6347
  - **Manhattan:** 212-851-4516
  - **Queens:** 718-670-1561
  - **Brooklyn:** 718-250-8708 or 1-866-442-2262
  - **Staten Island:** 718-226-6447

### New York State DOH Cancer Services

- 1-866-442-CANCER (2262)
- [www.health.ny.gov/nysdoh/cancer/center/partnerships/](http://www.health.ny.gov/nysdoh/cancer/center/partnerships/)

## American Cancer Society

- **1-800-227-2345 (24 hours a day)**
- **ACS Asian Initiative – Flushing, NY**  
41-60 Main Street Suite 307 Flushing, NY 11355  
Phone: 718-886-8890  
Hours: Monday-Friday, 9am-5pm
- **ACS Bronx Region Office**  
2426 Eastchester Road Suite 211 Bronx, NY 10469  
Phone: 718-991-4576  
Hours: 10am-2pm
- **ACS Manhattan**  
132 West 32nd Street NY, NY 10001  
Phone: 212-586-8700  
Hours: Monday-Friday, 9am-5pm

