

UID: _____

<u>DATE OF INTERVIEW:</u> Date ____/____/____ Location: _____	<u>INTERVIEWER INITIALS:</u> ____ <u>LHW INITIALS:</u> ____ <u>DATE:</u> ____
<u>PARTICIPANT'S INFORMATION :</u> Name _____ Home Phone _____ Cell Phone _____ Email Address _____ Address _____ Zip Code _____ How did you hear about the project? ____ Prior contact (friend, family member, etc) ____ Community Outreach Event ____ Website ____ Media (newspaper, poster, etc) ____ Email ____ Phone ____ Other (Explain): _____	
Are you willing to receive text messages and/or emails from the MARHABA study? ____ Yes ____ No	

UID: _____

My name is _____. I am with the MARHABA project, Muslim Americans Reaching for Health and Building Alliances.

Thank you again for agreeing to participate in this study.

MARHABA is collecting data to learn more about and respond to the issues that affect Muslim women around breast and cervical cancer screening.

We are conducting this study among Muslim female community members residing in the New York City metropolitan area. The study will consist of a baseline survey that will collect information on knowledge, beliefs, and practices regarding breast and cervical cancer. We will also be asking you other health-related questions and your experiences while accessing health care in the US. We will also be asking you to complete another survey in about 4 months. Your answers and ideas will help us better understand the issues that are important to your community and enable us to improve breast and cervical cancer screening behavior among Muslim women in NYC.

The survey will take approximately 40 minutes to complete. For your time, we will be providing you with a \$25 gift card after each survey is completed. Again, the information you provide in the survey is completely confidential. Please answer the questions based on your own experience or your own opinions. There are no right or wrong answers and if at any time you are confused about a question, please let me know.

CONFIDENTIAL

UID: _____

Demographics:

First, I would like to ask you some demographic questions.

1. What is your date of birth? _____

2. What is your zip code? _____

3. How would you describe your ethnicity?

_____ African American

_____ African

Country of origin _____

_____ South Asian

Country of origin _____

_____ Middle Eastern

Country of origin _____

_____ Southeast Asian

Country of origin _____

_____ Other

Country of origin _____

4. Were you born in the U.S.?

_____ Yes → Go to Question 5

_____ No → Go to Question 4a

4a. Which country were you born in? _____

4b. How long have you lived in the U.S.?

_____ years and _____ months

UID: _____

5. What is the highest grade or year of school you completed?

- _____ Never attended school or only attended kindergarten
_____ Grades 1 through 8 (Elementary)
_____ Grades 9 through 11 (Some high school)
_____ Grade 12 or GED (High school graduate)
_____ College 1 year to 3 years (Some college or technical school)
_____ College 4 years or more (College graduate)

6. What is your employment status?

- _____ Employed fulltime for wages
_____ Self-employed
_____ Part time (one job)
_____ Part time (multiple jobs)
_____ Student
_____ Unemployed for less than one year
_____ Unemployed for one year or more
_____ Retired
_____ Unable to work
_____ Homemaker/Housewife
_____ Other [WRITE IN] _____
_____ Don't Know
_____ Refused

7. What language(s) do you usually speak at home?

- _____ English
_____ Arabic
_____ Bangla
_____ French
_____ Other [WRITE IN] _____

UID: _____

8. How well do you ... ? [Read each line and indicate answer in table for each]

LANGUAGE FLUENCY/SKILL	Very Well	Well	Not Well	Not at All	Refused
a. speak English					
b. read English					
d. understand English					
e. speak home language					
f. read home language					
h. understand home language					

9. What is your marital status?

_____ Married

_____ Don't Know

_____ Living with Partner

_____ Refused

_____ Widowed

_____ Divorced

_____ Separated

_____ Never married

10. How would you describe your general health? [READ ALL; CHECK ONLY ONE]

_____ Excellent

_____ Don't know

_____ Very Good

_____ Refused

_____ Good

_____ Fair

_____ Poor

UID: _____

11. What kind of health insurance do you have?

- | | |
|--|------------------|
| _____ Private insurance/Work or company insurance | _____ Don't know |
| _____ Medicare | _____ Refused |
| _____ Medicaid | |
| _____ Other type of public/government insurance [WRITE IN] _____ | |
| _____ No health insurance. | |

12. How long has it been since you saw a health care provider for routine healthcare, not an emergency and not when you were sick or injured?

- | | |
|-----------------------------|------------------|
| _____ Less than a year ago | _____ Don't know |
| _____ 1-2 years ago | _____ Refused |
| _____ More than 2 years ago | |
| _____ Never | |

13. When you feel sick or become injured, what do you usually do?

- | | |
|---|------------------|
| _____ Go to a Private Doctor/Physician/Health Care Provider | _____ Don't know |
| _____ Go to a hospital outpatient department or hospital based clinic | _____ Refused |
| _____ Go to a Community Health Center or other Public Clinic | |
| _____ Go to the Hospital Emergency Room | |
| _____ Go to a Pharmacy | |
| _____ Use Traditional Healer/Medicine | |
| _____ Take Medicine at Home | |
| _____ I do nothing | |

14. Do you have a health care provider who speaks a language in which you can comfortably communicate?

- _____ Yes
- _____ No

UID: _____

15. In the last 12 months, were you unable to obtain medical care, tests, or treatments that you or a doctor believed necessary?

_____ Yes → Go to Question 15a

_____ No → Go to Question 16

15a. If yes, which of these best describes the main reason you were unable to get medical care, tests, or treatments that you or a doctor believed necessary?

_____ Couldn't afford care

_____ Don't have health insurance

_____ Insurance company wouldn't approve, cover, or pay for care

_____ Doctor refused to accept insurance plan

_____ Problems getting to doctor's office/ Transportation problems

_____ Different language

_____ Couldn't get time off work

_____ Didn't know where to go to get care

_____ Was refused services

_____ Couldn't get child care

_____ Didn't have time or took too long

_____ Other: [WRITE IN] _____

16. Please complete the following statement: "I prefer to receive medical care from a doctor or healthcare provider of..."

_____ My own race, ethnic, or religious group

_____ Another race, ethnic, or religious group

_____ I have no preference

17. Please complete the following statement: "I prefer to receive medical care from a doctor or healthcare provider who is ..."

_____ Male

_____ Female

_____ I have no preference

UID: _____

18. Screenings

	a) Have you ever received a check-up or screening for the following?				b) If yes, when did you receive this screening? (If no, skip to next screening type)				
	Yes	No	Don't know	Refused	1 year or less	1-2 yrs	2 or more years	Don't know	Refused
Blood pressure									
Cholesterol									
Diabetes/ High blood sugar									
Dental exam									
Colon cancer test: FOBT									

18a. Have you ever received a colonoscopy, a screening test for colon cancer?

_____ Yes → Go to Q18b.

_____ Don't Know

_____ No → Go to Q19

_____ Refused

18b. If yes, when was your last colonoscopy?

_____ Within the last 10 years

_____ Don't Know

_____ More than 10 years ago

_____ Refused

UID: _____

19. Has a doctor, nurse, or other health professional EVER told you that you have any of the following:

a. High blood pressure?

_____ Yes

_____ Don't Know

_____ No (not at all)

_____ Refused

_____ No, BUT told borderline high or pre-hypertensive

b. High cholesterol?

_____ Yes

_____ Don't Know

_____ No (not at all)

_____ Refused

_____ No, BUT told borderline high

c. Diabetes?

_____ Yes

_____ Don't Know

_____ No (not at all)

_____ Refused

_____ No, BUT told borderline high

d. Dental problems?

_____ Yes

_____ Don't Know

_____ No

_____ Refused

20. Have you ever been pregnant?

_____ Yes → Go to Question 20a

_____ Don't Know

_____ No → Go to Question 21

_____ Refused

20a. How many children do you have?

20b. Did your doctor tell you that you have diabetes during the pregnancy?

_____ Yes

_____ No

UID: _____

21. Have any of your immediate family members [father, mother, sister(s), or brother(s)] ever had the following health conditions, either here or in your home country?

	Yes	No	Don't Know	Refused
a. Hypertension/high blood pressure				
b. High Cholesterol				
c. Diabetes				
d. Heart Disease				

Mental Health:

22. Over the past two weeks how often have you been bothered by any of the following problems?

	Not at all	Several days	More than half the days	Nearly every day	PHQ# Value	Refused
MH1. Little interest or pleasure in doing things.	0 - <input type="checkbox"/>	1 - <input type="checkbox"/>	2 - <input type="checkbox"/>	3 - <input type="checkbox"/>		<input type="checkbox"/>
MH2. Feeling down, depressed, or hopeless.	0 - <input type="checkbox"/>	1 - <input type="checkbox"/>	2 - <input type="checkbox"/>	3 - <input type="checkbox"/>		<input type="checkbox"/>
Total (MH1 + MH2)						

If total ≥ 3 , administer follow-up survey at a later date

UID: _____

Health Information:

23. Does your household have a computer that connects to the internet or receives email?

_____ Yes

_____ No

**24. In general, where do you get information about your health and health services?
Select all that apply.**

_____ Family

_____ Don't Know

_____ Friends

_____ Refused

_____ Newspaper

_____ Ethnic newspaper

_____ Mainstream newspaper

_____ Both ethnic and mainstream newspapers

_____ Internet

_____ Ethnic Internet website

_____ Mainstream Internet website

_____ Both ethnic and mainstream websites

_____ At work

_____ Health care provider

_____ Social service programs

_____ Religious/spiritual leader

_____ Television

PERCEIVED ETHNIC DISCRIMINATION QUESTIONNAIRE

25. How often have any of the things listed below happened to you, because of your race or ethnicity?

How often...	Never	Sometimes			Very Often	NA
1. Have you been treated unfairly by teachers, principals, or other staff at school?	1	2	3	4	5	
2. Have others threatened to hurt you (ex: said they would hit you)?	1	2	3	4	5	
3. Have others actually hurt you or tried to hurt you (ex: kicked or hit you)?	1	2	3	4	5	
4. Have policemen or security officers been unfair to you?	1	2	3	4	5	
5. Have others made you feel like an outsider who doesn't fit in because of your dress, speech, or other characteristics related to your race?	1	2	3	4	5	
6. Have you been treated unfairly by co-workers or classmates?	1	2	3	4	5	
7. Have others hinted that you are dishonest or can't be trusted?	1	2	3	4	5	
8. Have people been nice to you in your face, but said bad things about you behind your back?	1	2	3	4	5	
9. Have people who speak a different language made you feel like an outsider?	1	2	3	4	5	
10. Have others ignored you or not paid attention to you?	1	2	3	4	5	
11. Has your boss or supervisor been unfair to you?	1	2	3	4	5	
12. Have others hinted that you must not be clean?	1	2	3	4	5	
13. Have people not trusted you?	1	2	3	4	5	
14. Has it been hinted that you must be lazy?	1	2	3	4	5	

UID: _____

26. How often have any of the things listed below happened to you because of your religion?

	Never	Sometimes			Very Often	NA
You are treated with less courtesy than other people	1	2	3	4	5	
You are treated with less respect than other people	1	2	3	4	5	
You receive poorer service than others	1	2	3	4	5	
A doctor or nurse acts as if he or she thinks you are not smart	1	2	3	4	5	
A doctor or nurse acts as if he or she is afraid of you	1	2	3	4	5	
A doctor or nurse acts as if he or she is better than you	1	2	3	4	5	
You feel like a doctor or nurse is not listening to what you were saying	1	2	3	4	5	

27. For these statements, I would like you to tell me if you strongly agree, agree, neither, disagree, or strongly disagree. Please listen carefully to each statement because you may agree with some but disagree with others.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Through my faith in Allah, I can stay healthy.					
If I lead a good spiritual life, I will stay healthy.					
If I stay healthy, it's because I am right with Allah.					
Living the way Allah says I'm supposed to live means I have to take care of myself.					
Even though I trust Allah will take care of me, I still need to take care of myself.					
Allah gives me the strength to take care of myself.					
I rely on Allah to keep me in good health.					
Allah works through doctors to heal us.					
Prayer is the most important thing I do to stay healthy.					
If I stay well, it is because of the grace of the good Allah.					
It's ok not to seek medical attention because I feel that Allah will heal me.					
There is no point in taking care of myself when it's all up to Allah anyway.					
Allah and I share responsibility for my health.					

UID: _____

28. On a scale of 1-10 how religious are you?

Not religious at all									Extremely religious
1	2	3	4	5	6	7	8	9	10

28a. How often do you attend religious services, classes, or other functions?

_____ More than once a week
 _____ Once a week
 _____ Once or twice a month
 _____ A few times a year
 _____ Seldom

_____ Refused
 _____ Don't Know
 _____ SKIPPED
 _____ Never

29. Please tell us how much you agree or disagree with the following statements.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
When I am in a mixed gender gathering or outside of the home, I cover my entire body, except my hands and face					
When I have guests at my home, men and women sit separately					
An unmarried man and unmarried woman should not be alone together					
I always look for a female doctor for myself					
I have delayed seeking medical care when no woman doctor is available to see me					
Hospital gowns are not modest					
My clothing demonstrated a commitment to Islamic modesty					
Maintaining Islamic modesty is important to me					

UID: _____

30. What is your TOTAL annual household income from all sources?

_____ \$0-9,999

_____ Don't Know

_____ \$10,000-19,999

_____ Refused

_____ \$20,000-29,999

_____ \$30,000-\$39,999

_____ \$40,000-49,999

_____ Greater than \$50,000

31. In the past 12 months, was there a time when you/your household didn't pay the full amount of the rent or mortgage because you didn't have enough money?

_____ Yes

_____ Don't Know

_____ No

_____ Refused

Now we are going to ask you questions about a disease called breast cancer, which is a cancer that occurs in the cells of the breast.

32. Have you ever heard of a mammogram, which is an X-ray picture of the breast?

_____ Yes

_____ No

33. Has your doctor ever told you to get a mammogram?

_____ Yes

_____ No

34. Have you ever had a mammogram, which is an X-ray picture of the breast?

_____ Yes

_____ No – Skip to Q36

35. IF you had a mammogram, when was your most recent mammogram?

_____ Less than 1 year ago

_____ 1 -2 years ago

_____ More than 2 years ago

_____ Other: _____

UID: _____

Breast cancer knowledge

Please answer if the following statements are TRUE or FALSE.

	True	False	Don't Know
36. Breast cancer is the most common cancer in the US and the world			
37. A mammogram is an X-ray picture of the breasts			
38. A woman between 50-74 years should get a mammogram every two years			
39. You don't need to get another mammogram if you had a normal one before			

40. Which of these is not a risk factor for breast cancer?

_____ Older age (over 50 years)

_____ Family history of breast cancer

_____ Obese or overweight

_____ Large breasts

41. We want to know how much you agree or disagree with the following statements about breast cancer.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
a. The thought of this disease scares me	1	2	3	4	5
b. Problems I would experience with this disease would last a long time	1	2	3	4	5
c. This disease would threaten a relationship with my partner	1	2	3	4	5
d. If I had this disease my whole life would change	1	2	3	4	5
e. If I developed this disease, I would not live longer than 5 years	1	2	3	4	5
f. This disease is caused by factors beyond human control, such as spiritual forces or fate	1	2	3	4	5
g. This disease can be cured if it found early	1	2	3	4	5
h. I have not thought about this disease at all	1	2	3	4	5
i. I do not know a lot about this disease so I do not have an opinion about it	1	2	3	4	5

UID: _____

42. Please tell us how much you agree or disagree with the following statements about a mammogram.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
a. When I get this recommended test, I feel good about myself	1	2	3	4	5
b. Having this test will help me find lumps early, before it can be felt by myself or a health professional	1	2	3	4	5
c. Having this test will decrease my chances of dying from breast cancer	1	2	3	4	5
d. Having this test will decrease my chances of requiring surgery if breast cancer is found	1	2	3	4	5
e. Having this test would make me worry about breast cancer	1	2	3	4	5
f. Many of my friends and family members receive this test	1	2	3	4	5
g. I am comfortable requesting this test from my doctor	1	2	3	4	5
h. I am very likely to get this test if a doctor recommended it	1	2	3	4	5
i. Having this test would be embarrassing	1	2	3	4	5
j. Having this test would take too much time	1	2	3	4	5
k. Having this test would cost too much money	1	2	3	4	5
l. I did not get this test because I did not know I needed one	1	2	3	4	5
m. I did not get this test because I did not have any symptoms	1	2	3	4	5
n. I did not get this test because the doctor did not recommend it	1	2	3	4	5
o. I do not know about this test so I do not have an opinion about it	1	2	3	4	5

UID: _____

Now we are going to ask you questions about a disease called cervical cancer, which is a cancer that occurs in the cells of the cervix, which is the lower part of the uterus.

43. Have you ever heard of an HPV test?

____ Yes ____ No

44. Has your doctor ever told you to get a HPV test?

____ Yes ____ No

45. Have you ever heard of a Pap test, which is part of the pelvic exam done at the doctor's office to check for cervical cancer?

____ Yes ____ No

46. Has your doctor ever told you to get a Pap test?

____ Yes ____ No

47. Have you ever had a Pap test?

____ Yes ____ No → Skip to Q49

48. IF you had a Pap test, when was your most recent Pap test?

____ 1 - 2 years ago

____ 3 - 4 years ago

____ 5 years ago

____ More than 5 years ago

____ Other: _____

UID: _____

Cervical cancer knowledge

Please answer if the following statements are TRUE or FALSE.

	True	False	Don't Know
49. Cervical cancer is 99% curable if found early			
50. A Pap test looks for changes in cells that could become cancer			
51. A woman who is at least 21 years old should start to get regular Pap tests every three years			
52. A Pap test affects your virginity			
53. You only need to get a Pap test if you are sexually active or are still getting your period			
54. You do not need to get a Pap test if you had a hysterectomy			

55. Which of these is NOT a risk factor for cervical cancer?

___ Young age

___ Family history of cervical cancer

___ Obese or overweight

___ Human papillomavirus infection (HPV)

56. We want to know how much you agree or disagree with the following statements about cervical cancer.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
a. The thought of this disease scares me	1	2	3	4	5
b. Problems I would experience with this disease would last a long time	1	2	3	4	5
c. This disease would threaten a relationship with my partner	1	2	3	4	5
d. If I had this disease my whole life would change	1	2	3	4	5
e. If I developed this disease, I would not live longer than 5 years	1	2	3	4	5
f. This disease is caused by factors beyond human control, such as spiritual forces or fate	1	2	3	4	5
g. This disease can be cured if it is found early	1	2	3	4	5
h. I have not thought about this disease at all	1	2	3	4	5
i. I do not know a lot about this disease so I do not have an opinion about it	1	2	3	4	5

UID: _____

57. Please tell us how much you agree or disagree with the following statements about a Pap test.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
a. When I get this recommended test, I feel good about myself	1	2	3	4	5
b. Having this test will help me find cancer early, before it can be found by myself	1	2	3	4	5
c. Having this test will decrease my chances of dying from cervical cancer	1	2	3	4	5
d. Having this test will decrease my chances of requiring surgery if cervical cancer is found	1	2	3	4	5
e. Having this test would make me worry about cervical cancer	1	2	3	4	5
f. Many of my friends and family members receive this test	1	2	3	4	5
g. I am comfortable requesting this test from my doctor.	1	2	3	4	5
h. I am very likely to get this test if a doctor recommended it	1	2	3	4	5
i. Having this test would be embarrassing	1	2	3	4	5
j. Having this test would take too much time	1	2	3	4	5
k. Having this test would cost too much money	1	2	3	4	5
l. I did not get this test because I did not know I needed one	1	2	3	4	5
m. I did not get this test because I did not have any symptoms	1	2	3	4	5
n. I did not get this test because the doctor did not recommend it	1	2	3	4	5
o. I do not know about this test so I do not have an opinion about it.	1	2	3	4	5

UID: _____

58. Please answer the following questions about your health behaviors.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly agree
a. I want to discover health problems early	1	2	3	4	5
b. Maintaining good health is extremely important to me	1	2	3	4	5
c. I search for new information to improve my health	1	2	3	4	5
d. I eat well-balanced meals	1	2	3	4	5
e. I exercise at least 3 times a week	1	2	3	4	5
f. I have regular health check-ups even when I am not sick	1	2	3	4	5

The next set of questions ask about the support you may receive from your husband, family, and friends for having a cancer screening.

	Never discuss	Low	Moderate	High	NA
59. How supportive is your <i>husband/partner</i> for you to get:					
a. Pap test	1	2	3	4	
b. HPV test	1	2	3	4	
c. Mammogram	1	2	3	4	
60. How supportive are your <i>family/relatives</i> for you to get:					
a. Pap test	1	2	3	4	
b. HPV test	1	2	3	4	
c. Mammogram	1	2	3	4	
61. How supportive are your <i>friends</i> for you to get:					
a. Pap test	1	2	3	4	
b. HPV test	1	2	3	4	
c. Mammogram	1	2	3	4	