Finding the major drivers of continuing late presentation of breast cancer in Southwestern and Northcentral Nigeria

Dear Respondent,

Good day, and thank you for your time. We want to seek your consent to ask questions about the lump in your breast over the next 20 to 30 minutes.

Let us to start by telling you our purpose

The purpose is to conduct a research about women’s treatment journey when they notice lump(s) in their breast. This research will assist us tremendously to understand how to improve our care of women who have the kind of lump in your breast.

The research is approved by the hospital and is being conducted by doctors who treat these kind of breast lumps in this hospital.

I am {the recruiter’s name: an investigator}.

I am one of the investigators in this research, with your consent I will invite someone who will be asking you questions and they will record your response. Every response you give will be confidential.

You can choose to respond or not respond as you wish.

If you like, you can choose to stop the session at any time, but as earlier state this should take about 20-30 minutes.

If you have any questions, you can ask me or your interviewer at any time in the course of this session and if you have any questions at the end of this session you can call any of these 2 numbers:

Local leads’ number:

Primary investigators’ number: +2348068756812

Please note that partaking in this question and answer session is not mandatory and will not affect your treatment in any way.

If you are willing to partake in this session, please sign/thumb print here before we proceed

Respondent’s Name: __________________________ Signature/thumbprint: __________________________
PERSONAL INFORMATION PAGE (to be completed by local lead investigator)

All fields are required. If not applicable please state “not applicable”
1. What first drew your attention to noticing this lump in your breast? (context creating aiding recall)

2. How long has it been since you first noticed it. [ ] days [ ] weeks [ ] months [ ] years

3. Use your finger(s) or fist to show me how big it was when it was first noticed. Describe patients’ response here and estimate the size in cm

4. Has it changed in size since the first time it was noticed? [ ] YES [ ] NO

5. If yes to (4) Please show me how big it is now using your finger(s) or your fist Describe patients’ response here and estimate the size in cm

6. Who are the people you that you discussed this lump with?: [ ] Mother/ father/ female siblings/ male siblings/ friends /neighbor / Husband / co-workers / doctor / Nurse / pharmacist/ chemist / CHEW /spiritual leaders / herbalist / others specify

7. Please re-trace the order in which these people in (6) were informed (the first person is Y, no names just relationships)

________________________________________________________________________________________
________________________________________________________________________________________
________________________________________________________________________________________

8. How frequently do you perform SBE. [ ] not performed [ ] daily [ ] weekly [ ] monthly [ ] occasionally

8b Have you had CBE or USS or Mammo in the past? [ ] Yes / [ ] No  (circle CBE, USS or Mammo as appropriate)

9. What was the interval between noticing the lump and telling the first person Y: [ ] days [ ] weeks [ ] months [ ] years

10. What was the first person(Y)’s advice/directive:

________________________________________________________________________________________

11. What was the advice or directive given by the others (specify person and directive)

________________________________________________________________________________________
________________________________________________________________________________________
________________________________________________________________________________________

12. What do you first do when you have health related problems or conditions such as fever, malaria etc
All fields are required. If not applicable please state "not applicable"
13 List the facilities and health persons you have visited to receive treatment or advice for this lump since you noticed it (e.g. hospital /chemist /pharmacy /Nurse /doctor)(for hospital specify: private, primary center, secondary center tertiary center):

________________________________________________________________________________________

14 Specify the first health personnel(X) you visited to receive treatment or advice: eg chemist, pharmacist, family doctor, specialist, CHEW (no names just cadre of personnel or facility) ________________________________

15 What was the interval between noticing the lump and visiting personnel X: ________________________

days   weeks   months   years

16 In the re-tracing in (7)above what is the position of this health personnel X: ________________________

17 Use your finger or fist to show me how big the lump was when you first visited personnel X:

Describe patients’ response here and estimate the size in cm ________________________________

18 What was the personnel X’s advice or directive?

________________________________________________________________________________________

What was the directive of other health persons(in 13 above)?

________________________________________________________________________________________

19 How long ago did you visit a pastor about this lump in your breast? ________________________

days   weeks   months   years

If yes, what is the position of the pastor along the re-tracing above: ________________________

20 What was the pastor’s advice/ directive?

________________________________________________________________________________________

21 How long ago did you visit an Islamic cleric about this lump in your breast? ________________________

days   weeks   months   years

If yes, what is the position of the Islamic cleric along the re-tracing above: ________________________

22 What was the Islamic cleric’s advice/directive?

________________________________________________________________________________________

23 How long ago did you visit a native healer about this lump in your breast? ________________________

days   weeks   months   years

If yes what is the position of the native healer along the re-tracing above: ________________________

24 What was the native healer’s advice/directive?

________________________________________________________________________________________

25 What is the native healer’s title (what people call him, how is he referred in your native language or dialect)

________________________________________________________________________________________

All fields are required. If not applicable please state “not applicable”
29 From whom or where did you first hear/learn about breast lumps?

__________________________________________________________________________

30 When, how long ago did you first hear about breast lumps

<table>
<thead>
<tr>
<th>days</th>
<th>weeks</th>
<th>months</th>
<th>years</th>
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(if don't know types, divulge that there are ordinary and cancerous types)

31 Breast lumps

__________________________________________________________________________

32 What treatment is given to ordinary breast lumps in the hospital?

__________________________________________________________________________

33 What treatment is given to cancerous breast lumps in the hospital?

__________________________________________________________________________

34 When/how did you first learn about the treatment given to cancerous breast lumps in the hospital

How? ______________________  When?  __________  day  ________  weeks  ________  months  ________  years

35 When/how did you first learn about the treatment given to ordinary breast lumps in the hospital

How? ______________________  When?  __________  days  ________

36 This lump in your breast, what was it called in the hospital (or what type was it called in the hospital)?

__________________________________________________________________________

37 What other names have people who are not medical personnel called this lump in your breast (pastor, Islamic cleric and native healers, friends, family and lay persons)

__________________________________________________________________________

__________________________________________________________________________

38 Do you know/have you heard (circle know or heard or both) about someone treated for ordinary breast lumps in the hospital before the lump in your breast was noticed? YES  NO

39 Where is the fellow now?

__________________________________________________________________________

40 Do you know/have you heard (circle know or heard or both) about someone treated for cancerous breast lumps in the hospital before the lump in your breast was noticed? YES  NO

41 Where is the fellow now?

__________________________________________________________________________

42 What options have you been offered by the various health personnel you have visited as treatment for this lump in your breast

__________________________________________________________________________

__________________________________________________________________________

43 What is your religion? Christianity / Islam / others specify:

__________________________________________________________________________

All fields are required. If not applicable please state “not applicable”
44 How far is your home from the referring hospitals? Quantify in hours’ drive: _____ hours’ drive:

45 Why did you decide to come here? (referred, not getting better, advice by friends etc.)

46. How far is your home from here? quantify in hours’ drive: ____________________________

47 What type of biopsy has been done? none / FNAC / Open biopsy

48 When was the biopsy done?

49 Where was the biopsy done?

50 What is the result of the biopsy: specify: ____________________________ / specimen not sent for testing / don’t know

51 if interval between noticing lump and visiting orthodox care is > 8 weeks ask why. Insert reason here: ____________________________

52 if interval between first orthodox visit and visiting doctor is > 2 weeks ask why. Insert reason here: ____________________________

53 if interval between visiting first doctor and visiting specialist is > 4 weeks ask why. Insert reason here: ____________________________

54 What is your pressing concern about hospital treatment offered to you for this lump (stressful, expensive, mutilating, Personnel attitude etc):

55. who to you first visit if you have to consult a health personnel for medical treatment:

56. If the place first visited for the care of her breast lump is different from the place usually visited for other illnesses in question 54 above, find out why:

57. If patient visited alternative care after first visiting hospital ask why:

58. If delayed or absconded after visiting specialist ask why. Insert reason here:

(final action: the local lead reviews questionnaire for completeness) Thank you very much, we are done.

58. Translator required during interview [YES] [NO]

------------------------------------------Lump information and signing off Section to be completed by local lead investigator------------------------------------------

Background information from patients’ case note.

Source of referral: specify:

Diagnosis:

Tumor size (cm):

Name of investigator

Signature