In-depth interviews with women who gave birth to preterm babies, low birthweight babies or babies who required care in NICU/SNCU

Instructions to the research team:
Participants in this IDI are women who have had a preterm birth, low birth weight baby or newborn who required care in the NICU/SNCU. This can include women of all ages, women who gave birth in the iKMC-implementing facility, in a birthing facility or in the home. It is preferable to identify women who have given birth in the last three months and whose baby is still alive. You can interview women currently in the facility prior to discharge or those who have already been discharged. The decision on who should be involved should be taken by the country study team.

If there is a specific terminology in the community used for preterm birth or low birth weight, please use this. You may need to explain some terms as you use them. For example, when discussing babies who required care in the NICU/SNCU, you may need to give some examples. Also, it may be better to ask her before the discussion some basic information about her name, the baby and the baby's name so that you can use these in the discussion. Below is a draft Introduction to the participant for your adaptation.

Introduction (to be read to participant):

Thank you for taking the time to speak to me today. My name is [interviewer name], and I am one of the iKMC-IR team members. Before we begin, can I please confirm that you have received a copy of the study information sheet and consent form?

As a reminder, this study aims to explore the care of babies who are born preterm, low birth weight or who need care in a newborn care unit/SNCU. We are interested in hearing your views and experiences related to pregnancy, childbirth, and care of your baby, including in the NICU/SNCU, as a woman who has had a preterm / low birth weight baby or a baby who required NICU care. You are free to answer in as much or as little detail as you wish, to not respond to any questions you do not wish to answer, and to pause or stop the interview at any time if needed.

There are no right or wrong answers. Everything you say will be treated confidentially and will not be shared with anyone outside of the iKMC-IR study team.

This interview will take approximately one hour, depending on how much you have to say. Can I please check you are free at the moment to talk for this amount of time?

I would also like to record our conversation- so that I can capture your responses accurately, and so that I can listen to you rather than take many notes. Can I confirm you are comfortable for me to start recording?

Thank you.

Data collection information (to be completed by the interviewer):

- Activity code:
- Date of interview
- Interview start time:
- Interview end time:
- Duration of interview:
- Interviewer name:

Information about participant to be collected prior to starting:

Socio-demographic information

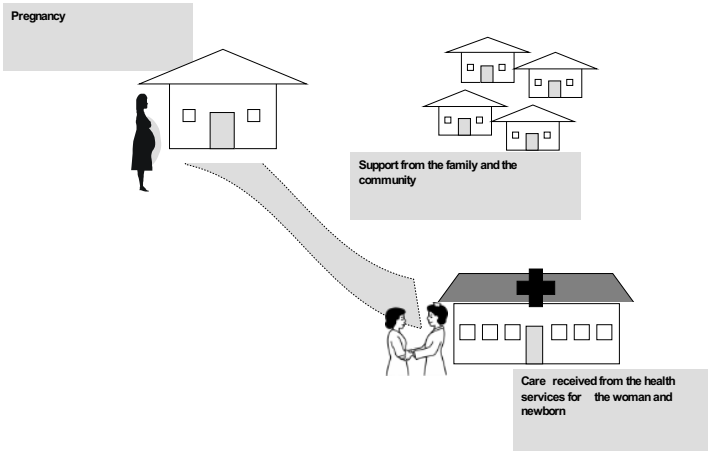
Community	
Place of interview	
Age (in years)	
Marital Status (married, unmarried, divorced etc.)	
Number of living children	
Ethnicity	
Religion	
Education (completed level)	
Occupation	
Month and year of baby's birth	
Sex of baby	
Singleton/Multiple	
Place of birth	
Baby's condition (if preterm, if LBW, if in need of care in the NICU/SNCU)	

SECTION A: JOURNEY MAPING

[Note to research team: *A journey map approach to maternity care acknowledges that often a woman's journey through ANC to childbirth and discharge and postnatal care includes several different health workers, levels of care and public and private sectors. A journey, from pregnancy to birth in this case, includes many economic, geographical, and sociocultural factors that must be navigated along the way and are additionally complex for women with preterm, LBW and babies in need of care in the NICU/SNCU. In this section we ask the woman a broad question about her journey from pregnancy to childbirth and care of her preterm, LBW or baby in need of care in the NICU/SNCU and you can prompt her with specific questions on the timeline, experiences, emotions, etc.*

Once the woman has had time to tell her story, the discussion guide thereafter can be used to fill the gaps in her journey with more specific/targeted questions related to the key themes.

Please could you take some time to tell me about your experience from when you realized you were pregnant, how you felt during pregnancy, any problems you had in pregnancy and where you went for these, and about when you went into labour and gave birth and what happened after birth for the care of you and your baby. Refer to the diagram below – at each point ask the woman to reflect on a) what happened at this point, b) how she felt, c) who else was involved in her care, d) what went well at this point, e) what could have been better?



SECTION B: DISCUSSION GUIDE

Antenatal care

In this part of the discussion, we would like to hear a little more about your experience in pregnancy, focussing on your pregnancy with your preterm/LBW/baby in need of care in the NICU/SNCU. I will build upon the information you just shared with me about your journey.

- Did you attend antenatal care?
  - If yes, where do you go for this (public/private, level of facility), and why there?
  - If not, what were the main reasons?

- Did you have an ultrasound? Where did you go for the ultrasound? What did you learn from the ultrasound report?
  - If you did not have an ultrasound, why not?
- Did the health worker at ANC identify any potential problems or conditions during your pregnancy?
- **If yes:**
  - How did they identify the problems? (e.g. did you have an ultrasound; did they do any other tests?)
  - What information or support were provided to you at this time? By whom?
  - What information did you receive about the rest of your pregnancy?

At this time did the ANC health worker mention the possibility of you having a small or sick newborn? How did you feel when you found out about the possibility of having a small or sick newborn? What were your concerns at this time?

- How did this change your decisions about childbirth? Please explain
- What information or advice did you receive about where to go for birth? From whom?
- During your ANC visits did you receive any information about caring for a preterm/LBW/ a baby who may need care in the NICU/SNCU ? Tell me about the information you received? Was this information useful?
- What are your suggestions for improving support for pregnant women who may have to prepare for their preterm /LBW/ baby who may need care in the NICU/SNCU?

Childbirth care

In this part of the discussion, we would like to understand about where you went to give birth and about the care you and your baby received. I will build upon the information you just shared with me about your journey.

- Where did you give birth? (e.g. home birth, facility birth (what level), public/private/NGO sector)
  - Why did you choose that facility?
  - Who else helped make the decision on where to give birth? (e.g. husband, mother, mother-in-law, other family, friend)
  - Who made the final decision? How did you feel about that?
  - If you found out in ANC that you were having a small or sick newborn, how did this change the decision making about where to give birth?
- I

*[**Note to research team:** Please modify the discussion according to where the mother gave birth to a preterm/LBW/ baby who required care in NICU/SNCU (either Section A <u>OR</u> Section B)].*

<u>If birth in a facility:</u>

- How did you get to the facility to give birth?
  - What challenges did you face in getting to the facility? (e.g. transport, cost, distance, terrain, other)
- Who accompanied you to the facility? (e.g. husband, family member, friend etc)
  - What support did they provide to you on the journey?
  - What support did they provide at the facility?

    - How did you feel about this support? Was it helpful?
    - Were there any challenges in them being able to support you at the facility? What were these?
- Did any health worker at the facility discuss your baby's weight with you?
    - Was your baby weighed after birth?
    - What information did you receive or what discussion was had after your baby was weighed? Who gave you information or discussed with you?
    - At this time, did the health worker mention that your baby was preterm/LBW or required care in a SNCU/NICU?
    - What did that person advise you to do? Were you able to follow that advice? Why or why not?
- How did you feel at this time?
    - Had you heard about preterm or LBW babies?
    - Tell me about what you had heard. [**Probe**: are these babies more vulnerable; any apprehensions regarding reactions by family, family support; any blame on her; any worries about the difficulties of taking additional care, etc]
    - What concerns did you have?
- What did you think about the care you received during birth? Could anything have been done differently that would have improved the care you and your baby received?

<u>If birth in a home:</u>

- Why did you choose to give birth at home?
    - Who else helped make the decision on where to give birth? (e.g. husband, mother, mother-in-law, other family, friend)
    - Who made the final decision? How did you feel about that?
    - Would you consider giving birth in a facility for a next birth? Why, why not?
- Who assisted you with the birth?
    - If a family member, who was this?
    - If a health worker, who was this?
    - If a community health worker, who was this?
- If someone else, who was this? Was the person who assisted you trained or a skilled birth attendant? Do you remember if your baby was weighed after birth? If yes, when was the baby weighed?
- Did anyone discuss with you or your family the baby's weight or that the baby was preterm/LBW or required care in a NICU?
    - If yes, who discussed? What did that person advise you to do? Were you able to follow that advice?
    - If no, how did you know that your baby was preterm/LBW or required care in a NICU?
- How did you feel at that time? what concerns did you have?
- What did you think about the care you received during birth? Could anything have been done differently that would have improved the care you received?

Referral

In this part of the discussion, we would like to understand if you and your baby were referred and hear about your experience. I will build upon the information you just shared with me about your journey.

- Were you or your baby referred from one facility to another or from home to a facility? Or was your baby referred within the facility to the NICU/SNCU?

    - Why were you or your baby referred? Who referred you?
- Were you able to follow the referral advice?
    - What challenges did you face in following the referral advice?
    - What did you think about this advice? What did family members think?
- Tell me about the referral experience:
    - Was it hard for you and your family to make the decision? Why?
    - When did you go to the facility, or to the NICU/SNCU? How long after birth?
    - How long did it take to reach the referral facility?
    - How did you get there?
    - Did you face any challenges getting there? (e.g. finding transport? Were there costs involved?)
- Did you and your baby travel together? How was the baby transported (e.g. with the mother/someone else/else/another caregiver? Was the baby transferred in skin-to-skin position? What challenges did you face in transporting you and the baby together?
- Did anyone talk to you about selecting a surrogate – or someone else who could accompany you and support you with the care of the baby? If so, who was selected and why?
- What was your immediate experience at the referral facility?
    - Were you admitted straight away?
    - Did they refer you somewhere else? Or send you back? Please elaborate.
    - How did you feel at this time? What concerns did you have?
- Is there anything about the referral process that could have been improved? Please tell me about anything that could have been done differently that would have improved the care you received.

Care of the baby after birth

In these next parts of the discussion, we would like to better understand the care your baby received while in the facility or at home.

***[Note to research team:** Please modify the discussion according to the baby's situation (i.e. whether the mother gave birth to a preterm or LBW, or a baby who required care in the NICU/SNCU].*

- How did you feel about the baby being born preterm/LBW/with other problems? Did you have any concerns? Please tell me more…
- What concerns did you have at this time?
- Was your baby cared for in any special way in the period immediately after birth?
    - **Probe**: what, how and why; bathing, cord care, clothing, massage with/without oil, where is baby placed – on the same cot as the mother, usual position of the baby; other care
- Was this care explained to you? By whom?
- Do you have any suggestions about how care at birth and immediately after birth could be improved for women who give birth to preterm or LBW babies or babies who need care in the NICU/SNCU ?

NICU or SNCU care

***[Note to research team:** Only apply this section if a baby was admitted to a NICU/SNCU.]*

In the next section, we would like to better understand the care your baby received and your own experiences while in the NICU/SNCU specifically. Here we will build upon the information you just shared about your journey.

- Please tell me about your stay in the NICU/SNCU?
  - How many days was your baby there? **Probe**: do you think your baby needed this care? Why/why not? What did you like or dislike about your stay?
- Were you able to stay with your baby? Did you have your own bed/chair/private space with your baby? If not, where did you stay?
- Where did you eat? Was it your family who brought you food? Or did the hospital provide food for mothers?
- Were you comfortable during your stay while your baby was in the NICU/SNCU? Why or why not? Please tell me more…
- How did you feel about the way health workers communicated with you? And with your family members? Did you feel you had sufficient information to answer your concerns? What else would you have liked to have known?
- What did you think about the staff who cared for you and your baby? Did you feel there was sufficient staff to provide needed care? Why or why not? How confident were you in their knowledge and skills to be able to support/care for you and your baby sufficiently? Why or why not?
- How did you spend your time during the first days while your baby was in the facility? Did you feel you learned how to take care of your baby while in the NICU/SNCU? Would you have liked to have been more involved in the care of your baby while in the NICU? Please tell me more…
- Were other family members allowed to visit you and your baby? Were they allowed in the NICU/SNCU? Did the health workers also talk to them?
- I had asked you above about a surrogate – or someone else who could accompany you and support you with the care of the baby – if you had a surrogate, what role did they play, how did they help?
- Did you yourself have any health concerns and how were you cared for while your baby was in the NICU? Tell me about how you were cared for. How was your own health? Did you require any additional care after birth? Do you remember what care you needed?
- Were you and your baby discharged by the doctor or did you leave early by your own decision? If you left by yourself, why?
- How did you feel about the length of stay in the facility? Who took care of your other responsibilities while you were in the facility (i.e. cooking, taking care of other children, etc.)? Did you have any concerns about the length of stay in the facility?
- Were you concerned about costs while your baby was in the NICU? What costs did you have to assume? How did you and your family cover these costs?
- Overall how did you feel at this point, what concerns did you have? How could care for your baby or yourself in the NICU/SNCU have been improved?

<u>Kangaroo Mother Care (KMC - skin-to-skin contact and exclusive breastfeeding)</u>
In the next section, we would like to know more about your feelings towards KMC including skin-to-skin contact and breastfeeding.

***[Note to research team:** The facilitator can show an image of skin-to-skin care.]*

I would like to talk about skin-to-skin care.

- Were you able to provide skin-to-skin care?
    - How long after birth did you start? Who supported you to provide skin-to skin?
    - What challenges did you encounter?
    - How did you overcome these?
- When did you learn about skin-to-skin care?
    - Who gave you information?
    - Would you have liked more information? On what aspects? How did skin-to-skin care help your baby?
- What kind of education /information/ support materials were provided to you on skin-to-skin care? [**Probe** on videos, posters, brochures, etc.]
- Were these useful to you and why or why not? What other materials would you have liked to receive?

*[**Note to research team:** Please modify the discussion according to where the mother did or did not initiate skin-to-skin care (either Section A OR Section B)].*

If mother-initiated skin-to-skin contact:

- What was your overall experience with skin-to-skin care? What did you like about the practice? What did you not like? Were there any challenges?
- Do you think your baby liked being in this position? What makes you think that?
- If your baby needed medical interventions/procedures, like support for breathing or IV fluids, do you think you would have been able to provide skin-to-skin? Why or why not?
- If we had asked you to start skin-to-skin earlier, immediately after birth and to continue – do you think you would have accepted this advice? Do you think you would have been able to do it? Why or why not?
- Approximately how long did you keep the baby skin-to-skin every day and for how long? If less than 24 hours per day, what stopped you doing this for longer periods of time?
- Did someone come remind you to provide skin-to-skin care? Who was that? Was this useful to you? Why or why not?
- Did someone from your family help you with skin-to-skin (did it for you, helped with positioning, helped with household chores)? Who? How? Would you have been able to continue skin-to skin contact and breastfeeding without this support?
- Would you recommend to other women to practice skin-to skin care for their babies if the baby needed this care? Why/why not? How would you convince a family member or friend to try the practice?
- What suggestions do you have to better support mothers and families to provide skin-to-skin contact?

If mother did not initiate skin-to-skin contact:

- What were your main reasons for not doing this? **Probe**: Were there medical reasons (because of fluid lines/tubes, oxygen etc.) for not initiating skin-to-skin? The family was against it? You were not well?
- Did the health workers encourage you to provide skin-to-skin contact? Did you see other mothers providing skin-to-skin contact?
- What would have been of support for you to do this? (visits from the health worker, family support, additional information)

I would like to talk about breastfeeding.

- Are you currently breastfeeding your baby ? Why or why not?
- When did you first put the baby to your breast? When did you start breastfeeding?
  - If born in a facility: were you supported by staff to breastfeed?
  - If born at home: did anyone support you to put the baby to the breast? Who?
- Did you face any challenge with feeding of your baby? Please tell me more…
- Did you feed colostrum? Why/why not?
- Did you give anything other than breast milk?
  - If yes, what and when? (i.e. water, formula milk, etc.)
  - Why did you give something else to the baby other than breast milk?
- Did you face any problem with breastfeeding? What were the problems? What did you do?
- Were you able to breastfeed with the baby in skin-to-skin contact? Did this pose any problems? If so, please tell me about this.
- If we had asked you to start exclusive breastmilk feeding earlier, immediately after birth and to continue – do you think you would have accepted this advice? Do you think you would have been able to do it?
- Were you given any breastfeeding support or advice?
- If your baby needed medical interventions/procedures, like support for breathing or IV fluids, do you think you would have been able to breastfeed?
- What kind of education /information/ support materials were provided to you on exclusive breastfeeding? [**Probe** on videos, posters, brochures, etc.] Were these useful to you and why or why not? What other materials would you have liked to receive?
- We would like to help mothers with preterm/LBW/ babies who need care in the NICU/SNCU to provide skin-to-skin contact and to exclusively breast milk feed – what suggestions do you have for us to better support mothers and families?

Discharge and follow-up care

In this section, we would like to understand how you felt about being discharged from the facility and the supports that were in place for when you returned to your home/family.

- When you and your baby were discharged, did health workers help you to understand how to take care of yourself and your baby at home? What did they tell you about?
- Did you feel ready to take care of your baby at home?
- Were you given any advice about providing skin-to-skin contact at home after discharge?
- How did you feel at this time? What concerns did you have?

*[**Note to research team**: If you are interviewing a woman before discharge, you will need to adapt this questions. i.e. When you return home will you be able to continue…]*

- When you retuned home, was it easy for you to continue to care for your baby? Was there anyone around to help you? Were you able to continue breastfeeding and skin-to-skin contact when you returned home? For how long? Why or why not?
- What other information or support would you have liked to receive? What other concerns have you had related to caring for your baby in the home? What challenges have you faced?

Wrapping up

- What suggestions do you have to better support mothers and families in the care of preterm/LBW/babies who require care in a NICU/SNCU?

- Do you think something else needs to be done to spread the knowledge about the benefits of skin-to-skin contact and exclusive breast milk feeding? What can we do to help mothers and families with preterm/LBW/babies who need care in the NICU/SNCU become interested in this practice?
- Are there any other issues that you feel are important and you want to mention before closing today's session?

Closing

Thank you for your time today. Your contributions will support the health services in better understanding how to improve care of newborns particularly those babies who are preterm/LBW or in need of care in the NICU/SNCU.