IDIs with family of women who gave birth to preterm babies, low birthweight babies or babies who required care in SNCU/NICU

Instructions to the research team:
Participants in these IDIs are family members of women who have had a preterm birth, low birth weight baby or newborn who required care in the NICU/SNCU. This can include their husbands, their mothers or mothers-in-law, aunties, or other family members This can include family of 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 family members of women who have given birth in the last three months and whose baby is still alive. You can interview family members of babies who are currently in the facility prior to discharge or those who have already been discharged. The decision on who would be involved should be decided by the country's study team.

You will need to adjust the discussion and your questions according to the person's relationship to the woman, i.e. if her husband, if her mother, if her sister. 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 sick babies, you may need to give some examples. Also, it may be better to ask before the discussion some basic information about the mother and the baby and their names so that you can use their names in the discussion.

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 are sick and require care in a newborn care unit. We are interested in hearing your views and experiences related to pregnancy, childbirth, and care of Baby C, including in the NICU/SNCU, as a family of a baby who was born preterm / low birth weight or required NICU/SNCU 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 now 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.)	
Ethnicity	
Religion	
Education (completed level)	
Occupation	
Relationship to the mother	
Relationship to the preterm/LBW/baby in need of care in the NICU/SNCU	
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)	

Discussion guide:

Antenatal and childbirth care

In this part of the discussion, we would like to understand about Mrs X's pregnancy and about where she gave birth and the care she and the baby received.

- When Mrs X was pregnant, did she receive antenatal check-ups? If so, how many and from whom?
- What kind of the support did Mrs X receive from you and other family members while she was pregnant?
- Was she or the family aware that she may have been at risk that the baby be born preterm/LBW/or might need NICU/SNCU care? If so, did you discuss this with Mrs X or within the family? How did you/how did the family react?
- Was she advised during pregnancy to give birth in a certain facility? Who advised this? Were you/family in agreement? If no, what were the reasons you did not agree?
- Where did she give birth (Probe, e.g. home birth, facility birth (primary, secondary tertiary), public, private or NGO sector)? Was this the recommended facility? Why did she give birth in this place? What role did family members play in the choice of place of birth?

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

A: If a facility birth:

- Were there difficulties in reaching the facility for birth e.g. Was transport easily available; were costs a problem distance, terrain? Any other barriers faced?
- Did a family member accompany Mrs X to the facility for birth? Was that person able to stay with her throughout labour and birth? If no, why not?
- After birth, was it discussed with you or with the family that the baby was preterm/LBW or required care in a NICU/SNCU? If yes, who discussed? What did that person tell you and advise the family to do? Did you discuss the advice with Mrs X or within the family? What was the reaction? Did the family decide to follow that advice or decide to do something else?
- How did you feel at that 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 or other community members, family support; any blame on the woman; any worries about taking additional care of the baby, etc.
- What did you think about the care Mrs X and the baby received during birth? What would you suggest be done differently that would have improved the care received during birth?

B: If a home birth:

- Why did the family prefer Mrs X have birth at home? Why didn't she go to a facility for birth?
- Who assisted the birth? Do you know whether the person was a trained health worker (skilled birth attendant)?
- Which family members were present during the birth?
- Would the family consider going to a facility for a next birth? Why/ Why not?
- Do you remember if the baby was weighed after birth? Who took the weight of the baby?
- After birth, was it discussed with the family that the baby was preterm/LBW or required care in a NICU? If yes, who discussed this with you? What did that person advise you to do? Did

you discuss the advice with Mrs. X and with the rest of the family? Was Mrs X able to follow that advice or did she decide to do something else? Tell me about what Mrs X did.

- How did you feel at that 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 the woman; any worries about taking additional care of the baby, etc.
- What did you think about the care Mrs X and the baby received during birth? What would you suggest be done differently that would have improved the care received during birth?

<u>Referral</u>

In this part of the discussion, we would like to understand if Mrs X and her baby were referred and hear about this experience.

- Were Mrs X and / or the baby referred from one facility to another or from home to a facility? Or were they referred within the facility to the NICU/SNCU? Why were they referred? Who referred them?
- Did the family comply with the referral advice? Why or why not?
- How was the decision for the referral discussed within the family and who made the decision?
- Can you tell me about the referral experience? Probe: Was it hard for you and your family to make the decision? Why? How long did it take to reach the referral facility? How long after birth was the referral? Could you easily find transport? Were there costs involved? Tell me about any difficulties faced.
- Did Mrs X and the baby travel together? How was the baby transported (e.g. Was the baby transferred in skin-to-skin position?)
- Did you or someone else accompany the baby and the mother? Why was this person chosen to go? Did this person stay with Mrs X and the baby to provide support during the facility stay?
- How were Mrs X and the baby received at the referral facility? Were they admitted or referred further or sent back? Please elaborate.
- Is there anything about the referral process that could have been improved? Please explain.

<u>NICU or SNCU care</u>

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

In the next section, we would like to better understand the care the baby received and your own experiences of the care and information given in the NICU/SNCU specifically.

- Can you tell me about the stay in the NICU/SNCU?
    - How many days was the baby there? Probe: duration of stay, staying arrangement, bathing, overall experience …]
- Do you think the baby needed this care? Why/why not? How did you/the family react when told that the baby had to stay in the hospital?
- What did you like or dislike about the NICU/SNCU stay? Why?
- Were you or another family member able to stay with you/Mrs X? Were you or the family member able to see the baby? Was it comfortable for Mrs X and for you or the family member who stayed with her? Why or why not?

- How did you feel about the way in which health workers communicated with Mrs X, you and / or the family? Did you understand how the baby was being cared for ? Did you feel you had sufficient information to answer your concerns? What else would you have liked to know?
- What did you think about the number of staff available? How confident were you in their knowledge and skills to be able to support/care for Mrs X and the baby sufficiently?
- Did you feel you / the family learned how to take care of the baby while in the NICU/SNCU? Would you have liked to have been more involved in the care of the baby while in the NICU?
- How was Mrs X cared for while the baby was in the NICU? Did she have any health concerns, and how were they addressed while the baby was in the NICU?
- How long did Mrs X and the baby stay in the facility? How did you and the family react to Mrs X being away from the home for this time? Who helped out with the household duties while Mrs X was in the facility (i.e. cooking, taking care of other children, etc.)?
- Did you feel Mrs X was worried while staying in the facility? If so, what caused the worry? Do you think Mrs X liked or disliked anything during her stay in the facility? Please tell us in detail.
- Was the family concerned about costs while the baby was in the NICU? What costs did you have to assume? How did you and your family cover these costs?

<u>Kangaroo Mother Care (KMC - skin-to-skin contact and exclusive breastfeeding)</u>

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

In the next section, we would like to know more about your knowledge of, and feelings towards KMC including skin-to-skin contact and breastfeeding.

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

- Did Mrs. X provide skin-to-skin care? How long after birth did she start? Did she find it difficult? What problems did she have? Were you supported by staff or someone e to provide skin-to-skin care?
- When did you learn about skin-to-skin care? Did you feel that Mrs. X and you as a family member received sufficient information about skin-to-skin care? Would you have liked additional information? What were you / the family told about the practice?
  - Probe: Length of time to do it, how to do it?
  - Which family members according to you can give SSC? Why do you say so?

- Do you understand well why this is recommended? Do you have any questions that remain unclear about skin-to-skin contact? Did you receive any kind of education /information/ support materials on skin-to-skin care? Probe on videos, posters, brochures, etc. Were these useful to you? Why? What other materials would you have liked to receive?

- What was the initial family reaction to providing skin-to-skin care? Were you supportive?
- Do you think Mrs X was adequately supported to provide skin-to-skin care? Were other family members asked to also provide skin-to-skin care? Did anyone not feel comfortable supporting skin-to-skin?

*[**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)].*

A: If mother initiated skin-to-skin contact:

- Do you think the baby liked being in this position? Did Mrs X like keeping the baby in this position? Why do you think so [were there signs of comfort/discomfort]?
- How long after birth did Mrs X begin practicing skin-to-skin contact? Why at that time?
- If we had asked Mrs X to start skin-to-skin earlier, immediately after birth and to continue – do you think she would have accepted this advice? Do you think she would have been able to do it?
- If the baby needed medical interventions/procedures, like support for breathing or IV fluids, do you think Mrs X would have been able to provide skin-to-skin? Why or why not?
- Would you recommend to other women to practice skin-to skin care if their babies required that care? Why/why not? How would you convince a family member or friend to try the practice?

B: If Mrs X. did not provide skin-to skin contact:

- What were the main reasons that Mrs X and the family did not provide skin-to-skin contact? Probe: Did health works not inform? The family was against it? Mrs X was not well? There were other ongoing medical interventions such as IV fluid, oxygen, CPAP, phototherapy etc.? Explain
- What could have been done to better support Mrs. X / the family to provide skin-to-skin care?

I would like to talk about breastfeeding.

- How did you feel about Mrs X providing breastmilk to the baby?
- Did you or others encourage her to give anything other than breast milk? What and when? (i.e. water, formula milk, etc.) If yes, why did you think she needed to give other liquids or food?
- Did Mrs X have any difficulties with breastfeeding? What were the problems? What was done to support her? Did you in particular do anything?
- Do you think adequate advice and support for breastfeeding were given by health workers?
- Did you or Mrs. X receive any kind of education /information/ support materials on skin-to-skin care? Probe on videos, posters, brochures, etc. Were these useful to you? Why? What other materials would you have liked to receive?
- If we had asked to start exclusive breastmilk feeding earlier, immediately after birth and to continue – do you think Mrs X, you / the family would have accepted this advice? Do you it was possible? Why or why not? Note: If not mentioned, ask: Did you feel the baby was too fragile?
- What kind of education /information/ support materials were provided 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 and families with preterm/LBW/ babies who require care in the NICU/SNCU to exclusively breast milk feed – what suggestions do you have for us to better support mothers and families?

<u>Discharge</u>

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

- When Mrs X and her baby were discharged, did health workers help her / you/ the family to understand how to take care of herself and the baby at home? What did they tell you about?
- Did you think Mrs X, you and the family felt ready to take care of the baby at home? What were your main concerns? What else would you have liked to have learned before leaving the facility?
- What other information or support would you have liked to receive? What other concerns did the family have related to caring for the baby in the home?

Wrapping up

- What suggestions do you have to better support mothers, parents, and families in the care of preterm/LBW/ babies who require care in a NICU/SNCU?
- Do you think something needs to be done to spread the knowledge about the benefits of KMC skin-to-skin contact and exclusive breastmilk feeding?
- What can we do to help mothers and families with preterm/LBW/babies in need of 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 .