## FGDs with community members and community leaders

***Instructions to the research team:***
Two people will be present during the FGD, comprising of one moderator and one note-taker (observer). This guide can be used for discussions with community members, community actors, community health workers, representatives of community groups and other people of influence in the community. If with community members, you may wish to have separate groups for men and women. The decision on who would be involved should be decided by the country study team.

You will need to adjust the discussion and your questions according to the participants. 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 certain terms during the discussion. For example, when discussing sick babies, you may need to give some examples.

**Introduction (to be read to participants):**

Thank you very much for taking the time to speak to me today. My name is [Facilitator name], am here today with (Note taker name). We are part of the iKMC-IR research team. 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 key barriers and facilitators to implementation of the different components of iKMC (care of preterm, low birth weight babies or babies who are sick and need care in a hospital special care unit for newborns). We are interested in hearing your views and experiences about how these babies are cared for and how we can improve care of these babies. You are free to answer in as much or as little detail as you wish, to skip over any questions you do not wish to answer, and to pause or stop the discussion 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 any of your colleagues, or anyone outside of the study team.

This discussion will take approximately 60 to 90 minutes - depending on how much you have to say. Can I please check you are all 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:
- Place of discussion:
- Date of discussion
- Discussion start time:
- Discussion end time:
- Duration of FGD:
- Facilitator name:
- Note-taker name:

**Information to collect (prior to starting):**

Socio-demographic information (for all participants involved in the FGD):

| | |
|---|---|
| Community | |
| Gender | |
| Age (in years) | |
| Marital Status (married, unmarried, divorced etc.) | |
| Ethnicity | |
| Religion | |
| Education (completed level) | |
| Occupation | |
| Organisations represented or role in the community | |
| Living in the community since how many months/years | |

## Discussion guide:

Care-seeking and childbirth care

*In this section, we would like to understand where women go for childbirth care and how they feel about the care they receive; we also want to know about women who give birth to a preterm baby (born too soon) or born small (low birth weight) or who was sick and required care in a newborn care unit and how others in the community perceive these babies.*

- Where do most women in your community go for childbirth care in your community? If in facilities: Please name the health facility most preferred for childbirth? Is it public/private/NGO facility? Do you know what level of care they provide: primary, secondary, or higher level? Why do women and families prefer this facility? Overall, what have you heard about the care they receive there? What are some things you would suggest to improve child birth care in health facilities ?
- How easy is it to reach a facility for childbirth care? Probe on distance, cost, road, time taken, etc. What are some of the difficulties women and families face? How can these difficulties be addressed so that women can get to childbirth care easier? What about if a pregnant woman was sick or had complications, where would you recommend she go? Why would you recommend there? Is it easy for women to get there? Why or why not?
- Do many women give birth in the home? If yes, what are the reasons for home birth? Why do some women and families not want to go a health facility for child birth? Do you personally think it is better to have birth in the home or in a facility? What are the reasons?
- If we wanted to encourage women to go to a facility for child birth care, Would community actors be willing to engage with us to support women to go to a facility for childbirth care? Why or why not? What role could community actors have and which should be involved?

Referral

*In this section we would like to understand what happens if women and newborn are referred from one place (from the home to a facility or from one facility to another facility) and how the referral system works.*

- If a preterm/LBW/baby in need of care in a NICU/SNCU is born at home, how is the newborn identified as preterm/LBW/in need of care in the NICU/SNCU care? Who would refer the baby to a health facility?
- What would be the reasons for the family not accepting the referral of the newborn?
- What challenges would they face in getting to the facility?
- If a mother and baby need to be referred from a birthing unit to another facility that offers more specialized care, would most families accept this advice? If not, why not? What challenges would the family face in getting to the facility? Are there costs? Who would pay the costs? Is there transport available?
- How do you think these different challenges can be overcome?
- In general how can you as community members/leaders provide support to improve access to health facilities for the mothers and their babies?

Perceptions of NICU care

- If a baby is born preterm/LBW/in need of care in the NICU/SNCU , they may require care in a special newborn care unit in a hospital – Do you have anything like that in your community? Where is that? How do you know about the facility/facilities? What have you heard about this care? Are babies well cared for in this facility? Does the community feel the staff has

the needed skills? What do you think can be done to improve care for babies who are born preterm/LBW/in need of care in the NICU/SNCU at this/these facilities?

- When a baby needs care in the NICU/SNCU and has to stay at the hospital, who usually stays with the baby? What are the difficulties they may face for staying at the hospital for the baby who needs care in the NICU/SNCU? If a woman is staying with her newborn in a facility while the baby is being cared for, what kind of support is available to her to care for her home and other children and other responsibilities?
- Do the husbands and other family members accompany the mother and newborn while the baby is admitted in the health facility? What support can they provide? How do men feel about being involved in this care? How could we engage with men partners /fathers so that they were more open to participating in the care of their preterm/LBW/baby in need of care in the NICU/SNCU?

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

*In this section we are interested in learning about what you know about Kangaroo Mother Care (KMC skin-to-skin contact and exclusive breastfeeding), we would like to know about how you and others in the community feel about the practice and how you could support the practice in your community.*

**Facilitator shares a picture of a baby receiving skin-to-skin care**

- Have you heard or seen this practice before? How did you learn about this practice? What do you know about this?
- The woman in the picture has had an early baby or a small baby and is in the hospital after birth, she is keeping the baby skin-to-skin as many hours of the day and night possible to keep the baby warm and breastfeeding as often as she can. How would you feel if you/your wife/your daughter/your friend was asked to do this?
- Do community members know about skin-to skin contact? From where did they learn about this?
- Do you think people in the community would approve or disapprove of this practice? What concerns would they have about this practice? Probe: For mother, baby and for the family in general.
- If people would disapprove the practice, what do you think should be done to help them learn about and accept the practice? How could community leaders help to support?
- Do most women in this community exclusively breastfeed their babies? Up to what age? If not, what other liquids or foods do they give their babies? Why is that?
- How can we engage community leaders to help to support exclusive breastfeeding, especially for preterm or LBW babies?

<u>Social norms regarding preterm/LBW/babies in need of</u>care in the NICU/SNCU

*In this section we are interested in learning about how community members react to women having preterm/LBW/babies in need of* care in the NICU/SNCU *and how women and families are supported.*

- We have talked a lot about preterm/LBW/ babies in need of care in the NICU/SNCU . We were interested in knowing how community members respond if a baby is born with any of these conditions? Are there any beliefs about why babies are born this way? Would a woman and her family be supported by the community when a preterm/LBW baby is born? Is there any stigma associated with these conditions?
- If we would like to build family and community support so that these babies are better cared for in the health services and in the home, what suggestions do you have for us?

Influencers and delivery channels

*In this section we want to understand who are the most trusted sources of information for women on newborn care, who influences women's decisions and how your community can support women and families whose preterm, LBW or babies in need of care in the NICU/SNCU*

- Who do people trust most to receive advice about newborn care? Where would a woman go if she needed information about her newborn who was preterm/LBW/ in need of care in the NICU/SNCU?
- Where do people in the community get information about newborn health? Which source of advice do you think they trust most and why? Probe: Family, friends, neighbours, newspaper, TV/Radio, social media, Religious leaders, community groups, community health workers, health services, etc.
- Do you know of any success or achievements in efforts to strengthen community support for care for newborns who are preterm/LBW/ in need of care in the NICU/SNCU?
- If we wanted to encourage mothers, parents, and families to better care for preterm/LBW/ baby in need of care in the NICU/SNCU - what would be the best way to do this?
- If we want to improve care for newborns who are preterm/LBW/ in need of care in the NICU/SNCU , what actors/groups should we involve?

Wrapping up

- Are there any other issues that you feel are important and you want to mention us before closing the session?

Closing

Thank you for your time . 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.