IDIs/FGDs with community health workers

Instructions to the research team:
Some sites would like to do IDIs, and others would like to do FGDs with community health workers - please prepare and adapt this instrument accordingly. If an FGD, two people will be present, comprising of one moderator and one note-taker (observer). The decision on who would be involved and what type of method 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 babies who need additional care, 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 the 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:
- Date of discussion
- Place of discussion:
- Discussion start time:
- Discussion end time:
- Duration of FGD:
- Facilitator name:
- Note-taker name:

Information about the health facility:

- Name of health facility:
- Code number of the facility (as per facility mapping information if available):
- Area:
- Type of facility (public, private, NGO etc.):
- Level of facility:

Information to collect (prior to starting):

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

Community	
Age (in years)	
Gender	
Education (completed level)	
Education (completed level)	
How long worked in current role?	
Overall duration of experience as CHW	
Organization represented	
Living in the community since how many months/years	

Discussion guide:

Antenatal care

In this section, we would like to understand the role of community health workers in supporting women during pregnancy including women who have been identified as high risk of having a preterm baby (born too soon) or low birth weight (born small) baby.

- Are you involved in the providing ANC services to pregnant women? What is your role?
- In your community, do most women seek antenatal care from the health services? How many visits do they usually have? If women do not go to antenatal care, why do they not go?
- How do you identify pregnant women in your catchment area? How effective is the approach? What are some of the challenges?
- As part of ANC are some women identified at risk of preterm/LBW babies? If so, how are they identified? What is your role after you find out about this? **Probe**: what information would you share with her, are you to provide any support and if so, what?
- Are women identified as having a preterm/LBW/ or a baby who may require additional care encouraged to attended childbirth in a facility? Where are they told to go for childbirth care? Do you have any role in helping them to prepare for birth and get to the facility? Tell us about your role.
- Could anything different be done in ANC or during a women's pregnancy that would help to better support her in preparing for a preterm /LBW/or baby who may require additional care?

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 or LBW baby or a baby who required care in a newborn care unit/SNCU.

- 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? What level of care is provided:_ primary, secondary, higher level? Why do women and families prefer this facility? [**Note**: **Probe** for distance, availability of transport, cost of transport, free consultation and medicines, respectful care, family decision, absence of a female doctor, etc.]
- Overall, what do women think about the care they receive there? What are some things you would suggest to improve child birth care in these health facilities?
- What about if a pregnant woman was sick or had complications, where would you recommend she go? Why would you recommend there? Is this place easy for women to get to? 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?
- Are you informed about the birth when it happens in the home? What do you do once you learn about the birth?
- Do you think it is better to have births in the home or in a facility? Why?
- If we wanted to encourage women to go to a facility for child birth care, what suggestions do you have for us? Are there any community actors with whom we should engage? Which community actors should be involved and how could they support?

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.

- How do community health workers know if a birth is early (preterm) or if the baby is born too small?
- What do you do if you are advised of woman who goes into labour that starts before the baby is due?
- What do you do if you identify a baby born in the home who is preterm/LBW or who needs care in the NICU/SNCU and needs to go to the facility?
- How do you support women and babies who need to get to a facility after birth? Can you tell me about referral experiences: Is it hard for women and families to make the decision? Why is that? Can they you find transport? What costs are involved? How acceptable to them are referrals to a facility? Do people go if you advise them to go? What are the reasons for compliance/non-compliance to referral?
- Do mothers and babies travel together? Who else would usually accompany the baby to the facility? What challenges would they face in getting to the facility?
- How are babies transported (e.g. with the mother/surrogate/other caregiver? Are babies transferred in skin-to-skin position?
- Is there anything about the referral process that you think should be improved?
- 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?

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 near 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 mothers 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?
- Do the husbands and other family members accompany the mother and newborn while the baby is admitted in the health facility? What role can they play to support? 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 who needs care in the NICU/SNCU?

KMC (skin-to-skin contact and exclusive breastfeeding)

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?
- Do you know how it is done? Do you currently support this in the community where you work? If yes, what support do you provide? If no, are there any plans to implement this in facilities or in the community?
- Do you think it is easy for woman and families to provide skin-to-skin contact?
- A mother with preterm or small baby is expected to keep the baby skin-to-skin day and night and exclusively breastfeed the baby. Do you think mothers can do this? Why/Why not?
- Is this practice promoted in this area?
    - **Probe**, if yes: Have there been any challenges? What are the most important lessons that have been learned about promoting this practice?
- Have you ever supported mothers to do this? How do mothers respond to counselling and advice to provide skin-to-skin-contact?
- Do you feel you have the required expertise to support this practice? **Probe**: Training (specific training on KMC as part of other training), time, education materials, etc.
- I want to talk a little more about breastfeeding. Do most women breastfeed their babies? Do they give anything other than breast milk? What and when? (i.e. water, formula milk, etc.)
- What problems do they face with breastfeeding?
- Tell me about what breastfeeding support or advice you provide?
- We would like to help mothers with preterm/LBW/babies in need of 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? What role can you have?

<u>Training</u>

In this section we are interested to learn about what training community health workers have received on KMC (and iKMC) and their perceptions of their ability to support KMC care for women and their preterm/LBW/babies in need of care in the NICU/SNCU.

- Have you ever taken part in training on the care of preterm/LBW babies? When? What topics did you cover in the training?
- Have you received training on KMC (what it is/how to support women to implement it…) When? What topics did you cover in the training?
- Do you feel prepared to promote KMC and care for preterm and LBW babies?
- What additional support or training would you like in order to provide better support to women and families with preterm or LBW or babies in need of care in the NICU/SNCU including for identification of these babies for referrals, for counselling and health education activities, for follow-up care?

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

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 requiring special newborn care. 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? Is there any stigma associated with these conditions?

- What do people in your community think are some of the reasons for having a preterm baby? What do they think causes a baby to be born before its due date?
- What do people in your community think about babies who are born low birth weight or too small?
- If a woman has a baby that is either preterm/LBW/ or who has been sick – who do women get support from? Can they count on their husband, their family, their neighbours for support?
- What role do you have while the woman is in the facility with her baby? How do you know when the woman and baby come home? What role do you have when they come home?
- 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 the most trusted sources of information for women on newborn care are, who influences women's decisions and how your community can support women and families whose preterm, LBW or babies who need 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, etc.
- If we wanted to encourage mothers, parents, and families to better care for preterm/LBW/babies 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 additional care.