

Supplementary Material S1: Interview Guide

Study Title: Caregivers' experiences of seeking care and barriers to access in child illness that led to death in rural South Africa

*** This interview guide was developed following extensive reading around the topic. discussions with experienced social scientists (LH and JS), as well as context experts (KK and JS), and population-based research conducted in the Agincourt and AHRI HDSS sites on under-5 mortality, including the completion of verbal and social autopsies for all under-5 deaths in the HDSS sites to better understand the circumstances of death and barriers to accessing healthcare during the final illness.*

Interview Guide (Key Informant Interviews):

*Note: Consent to be taken before starting the interview. Interviewer to then start by introducing themselves, reminding the participant they will be audio-recorded, they can refuse to answer any questions and/or pause the interview.

Possible introductions:

"I want to talk about your child's death but before we talk about that, I would like to ask a few general questions to understand more about your family and your daily life".

- 1) Respondent's relationship to the child
- 2) Family structure, how many members in the household, how many children, and how old are they, anyone working, any previous deaths in the household (esp child deaths).
- 3) Relationship to community, do they feel close to the community, are they well integrated?
- 4) Religion, and role of religion in daily life.
- 5) For Agincourt and if Mozambican: how do you think being Mozambican affects your daily life here? How does it affect your experience and access to health care?

"I have some questions about your child's death that I want to ask but I am really interested in hearing about your experience in your own words. I expect that some of my questions will be answered in your story, so I would like to hear from you first. "

- 1) Can you tell me about your child's final illness? About how it started, when you first started noticing symptoms, what you did etc. (allow participant to finish their story without interruption. If not supplied, then probe for symptoms recognised, what they did in response to those symptoms, where they sought care and when)
- 2) Can you tell me about your experience of seeking care?

- a. Explore where they went for care
 - b. Why did they choose to go where they did?
 - c. (if Mozambican: might probe with :do you think your experience of seeking care was in any way related to your being Mozambican?"
- 3) How did the staff treat you?
- (Probe for positive and negative experiences, how did the staff treat them, were they made to wait, were they allowed to stay with their children during any treatments/procedures – and did they like this or not?)
- *If they didn't seek care, explore issues around why they didn't access care.
- *any causes of major delays in seeking care
- 4) What treatment did you get from the provider? What advice did the provider give you? Were you referred somewhere else?
- 5) Explore whether they completed/complied with the treatment, why or why not, if referred did they take up the referral?
- 6) Traditional medicine used/visited traditional healer? - why?
- 7) Can you tell me about any challenges you faced in accessing healthcare? Is there anything that made is difficult to get healthcare?
- 8) Why did you go to your chosen healthcare facility or provider?
- 9) How did you overcome those difficulties?
- 10) Were you satisfied with the care you were offered? Is there anything that could have been done better?
- 11) Is there anything else you want to tell me?