Study ID# ☐☐☐☐–☐☐☐–☐☐☐

Village/Cluster HH Child

Module 6: Care-seeking for the child's fatal illness (FOR NEONATAL & CHILD DEATHS 0—59 MONTHS OLD)

Read: Now, I'd like to ask you about <NAME>'s fatal illness and the care and treatments that s/he received.

S6.1	Who first noticed that <NAME> was ill?	1. The respondent 2. Other relative, neighbor, friend 3. CHW/nurse at home or community 4. Doctor/nurse at a health facility 5. Other *(specify)*	☐ _____

S6.2	Earlier you said that <NAME> had <SYMPTOM(S)> during her/his illness. *[Read back all the child's VA symptoms from the list in GQ1.10 (for neonates) or GQ1.11 (for children.]* How did <SQ6.1 PERSON> first know that <NAME> was ill? Which of these symptoms did s/he have at that time? What symptoms did s/he have next? On what day of the illness did these symptoms start? *[Probe until all the symptoms are recorded in the order they appeared.]*	**Symptoms in order of appearance**	**Illness day the symptom started**
		1.	
		2.	
		3.	
		4.	
		5.	
		6.	
		7.	

S6.3	When <SQ6.1 PERSON> first noticed that <NAME> was ill, was s/he… *[Read the choices for each condition.]*	1. Feeding normally, poorly, or not at all ... 2. Alert, drowsy, or unconscious................ 3. Normally active, less active than normal, or not moving	Normal Medium Abnormal DK 1.☐ 2.☐ 3.☐ 9.☐ 1.☐ 2.☐ 3.☐ 9.☐ 1.☐ 2.☐ 3.☐ 9.☐

S6.4	Did <NAME> receive, or did you <u>seek</u> or <u>try</u> to <u>seek</u>, any care or treatment for the fatal illness?	1. Yes 2. No—care not needed, given or sought 3. No— died immediately 9. Don't know	☐ *2 → SQ6.6* *3 or 9 → Open History*

S6.5 Please tell me everything you did for <NAME>'s fatal illness inside the home and all the places outside the home you <u>took</u> or <u>tried</u> to take (her / him) for health care. Start with the first care or treatment <NAME> received and then, in order, tell me all the other care and treatments s/he received. Also tell me when and for what symptoms you took each action.

[Include any provider <NAME> did not reach because s/he died before leaving home or on route.]

(1) Check <u>one</u> other care <u>or</u> health provider box for each action row. (2) For neonatal deaths only: If the illness began at the health provider where the child was delivered, then mark that as Action 1 and check the "illness began at provider" box. (3) Record the illness day each action was taken. (4) Ensure no action was taken for a symptom before it started (in SQ6.2).

Action #	**(1) Other care**			**(1) Health Providers**				**(2) Illness began at provider where child was delivered**	**(3) Illness day the action was taken**	**(4) For what symptom(s) was the action taken?**
	Home care (own, relative, neighbor, friend)	Tradi-tional or non-formal provider	Phar-macist or drug seller	Trained CH Worker, nurse, or midwife	Private doctor (formal/ unsure)	NGO or govt. clinic	Hospital			
1.	☐	☐	☐	☐	☐	☐	☐	☐	___ ___ *(DK = 99)*	
2.	☐	☐	☐	☐	☐	☐	☐	▓	___ ___ *(DK = 99)*	
3.	☐	☐	☐	☐	☐	☐	☐	▓	___ ___ *(DK = 99)*	

4.	☐	☐	☐	☐	☐	☐	☐		___ ___ *(DK = 99)*
5.	☐	☐	☐	☐	☐	☐	☐		___ ___ *(DK = 99)*
6.	☐	☐	☐	☐	☐	☐	☐		___ ___ *(DK = 99)*
7.	☐	☐	☐	☐	☐	☐	☐		___ ___ *(DK = 99)*

***Inst_1: (For neonatal deaths only) If illness began at health provider where child was delivered:
And did not fill L&D matrix (module 4) → SQ6.10;   And filled L&D matrix (module 4) → SQ6.16***

S6.6	*If no care given or sought, ask:* Who decided that <NAME> did not need any care or treatment for the illness? *If any care given or sought, ask:* Who decided that <ACTION 1> was the first thing to do for <NAME>'s illness? *[Record the one main decision maker.]*	1. Child's mother .... 2. Child's father .... 3. Child's aunt.. 4. Child's uncle .... 5. Child's grandmother .... 6. Child's paternal grandfather .... 7. Child's maternal grandfather .... 8. Other *(specify)*...................................... 9. Don't know	1. ☐ 2. ☐ 3. ☐ 4. ☐ 5. ☐ 6. ☐ 7. ☐ 8. ☐ _____ 9. ☐
S6.7	*If never taken to a health provider, ask:* Did you have any concerns or problems that kept you from taking <NAME> to a health provider during his/her illness? *If taken to a health provider, ask:* Did you have to overcome any concerns or problems to take <NAME> to the (first) health provider?	1. Yes 2. No 9. Don't know	☐ **2 or 9 → Inst_2**
S6.7.1	What concerns or problems did you have? *Prompt:* Was there anything else? *[Multiple answers allowed.]*	1. Did not think child was sick enough to need health care..................................... 2. No one available to go with caregiver..... 3. Too much time from her regular duties .. 4. Someone else *(specify)* had to decide ... 5. Too far to travel .... 6. No transportation available.................... 7. Cost (transport, health care, other) .... 8. Not satisfied with available health care .. 9. Problem required traditional care .... 10. Thought child was too sick to travel...... 11. Thought child will die no matter what.... 12. Was late at night (transportation or provider not available) .... 13. Other *(specify)*.................................... 99. Don't know	1. ☐ 2. ☐ 3. ☐ 4. ☐ _____ 5. ☐ 6. ☐ 7. ☐ 8. ☐ 9. ☐ 10. ☐ 11. ☐ 12. ☐ 13. ☐ _____ 99. ☐

***Inst_2: If SQ6.4 = 2 (No care given) or
If SQ6.5 ≠ "Health Provider" (Never took and never tried to take to a health provider) → SQ6.39***

S6.8	*Refer to SQ6.5 for the first health provider and related symptoms:* You mentioned that you took <NAME> to the (first) health provider, I mean the <FIRST HEALTH PROVIDER> for <SYMPTOM(S)>. How long had <NAME> had (this / these) symptom(s) when it was decided to take him/her to the <FIRST HEALTH PROVIDER>? *[Read "…to the first…" if took or tried to take to more than one health provider.]* *[Mark days, hours &/or minutes as needed: e.g. 00 day, 02 hours, 10 minutes]*	___ ___ Days *(DK = 99)* ___ ___ Hours *(DK = 99)* ___ ___ Minutes *(DK = 99)*

Child illness matrix instructions: *Ask the following questions for the <u>first</u> and <u>last</u> health providers where care was sought or tried to be sought for the fatal illness. Ask all the questions for the first provider before going on to the last.*

Before asking about the first health provider, read:
Now I would like to ask you about your visit to the (first) health provider. *[Read "first" if went or tried to go to more than one provider.]*

Before asking about the last health provider, read:
Now I would like to ask you about your visit to the last health provider, I mean the <LAST HEALTH PROVIDER>.

– CHILD ILLNESS MATRIX QUESTIONS –		FIRST HEALTH PROVIDER	LAST HEALTH PROVIDER
At the time when it was decided to take <NAME> to the <FIRST/LAST HEALTH PROVIDER>, was s/he… *[Read the choices for each condition.]*	1. Feeding normally, poorly, or not at all.. 2. Alert, drowsy, or unconscious ...... 3. Normally active, less active than normal, or not moving.................	S6.9 <u>Nrml</u> <u>Med</u> <u>Abnrm</u> <u>DK</u> 1. □ 2. □ 3. □ 9. □ 1. □ 2. □ 3. □ 9. □ 1. □ 2. □ 3. □ 9. □	S6.24 <u>Nrml</u> <u>Med</u> <u>Abnrm</u> <u>DK</u> 1. □ 2. □ 3. □ 9. □ 1. □ 2. □ 3. □ 9. □ 1. □ 2. □ 3. □ 9. □
What was the name of the <FIRST/LAST HEALTH PROVIDER> where you took <NAME>? *Probe to identify the type of provider.*	1. Hospital (Government) 2. Hospital (NGO) 3. Hospital (Private) 4. Health center (Government) 5. Health center (NGO) 6. Health post (Government) 7. Health post (NGO) 8. Private doctor/clinic (Formal) 9. Private doctor/clinic (?Formal?) 10. Trained community health worker, nurse, or midwife 99. Don't know	S6.10 □ □ _____ (Name of Provider or Facility)	S6.25 □ □ _____ (Name of Provider or Facility)
After (deciding to seek care / being referred), how much time passed before going to the <FIRST/LAST HEALTH PROVIDER>? *[Discuss that this might include the time needed to arrange for transportation and money to go to the provider/facility, or to provide home care or go to a traditional provider before going to the health provider.]* *[If the child died at home, record the time from decision/referral to death.]* *[Mark days, hours &/or minutes as needed: e.g. 01 day, 05 hours, 30 minutes]*		S6.11 ___ ___ Days *(DK = 99)* ___ ___ Hours *(DK = 99)* ___ ___ Minutes *(DK = 99)*	S6.26 ___ ___ Days *(DK = 99)* ___ ___ Hours *(DK = 99)* ___ ___ Minutes *(DK = 99)*
Was there any cost to travel to the <FIRST/LAST HEALTH PROVIDER> or pay for the child's care there?	1. Yes 2. No 9. Don't know	S6.12 □ **2 or 9 → 6.13**	S6.27 □ **2 or 9 → 6.28**
How did you arrange for the money for these expenses? *[Multiple answers allowed.]*	1. Had available .... 2. Borrowed....................................... 3. Sold assets .... 4. Help from kin/relatives .... 5. Community fund............................. 6. Govt. scheme................................ 7. Other .... 9. Don't know	S6.12.1 1. □ 2. □ 3. □ 4. □ 5. □ 6. □ 7. □ 9. □	S6.27.1 1. □ 2. □ 3. □ 4. □ 5. □ 6. □ 7. □ 9. □
What transportation method was used to go there? *[Multiple answers allowed.]*	1. Walk... 2. Rickshaw/cart/boat....................... 3. Bus.. 4. Taxi/auto/trecker .... 5. Ambulance .... 6. Other .... 7. Could not arrange transport .... 9. Don't know	S6.13 1. □ *If <u>only</u> walk* 2. □ *→ SQ6.14.1* 3. □ 4. □ 5. □ 6. □ 7. □ *→ SQ6.14.1* 9. □	S6.28 1. □ *If <u>only</u> walk* 2. □ *→ SQ6.29.1* 3. □ 4. □ 5. □ 6. □ 7. □ *→ SQ6.29.1* 9. □
How much did the transportation cost?		S6.14 ___ ___ ___ ___ unit *(DK=9999)*	S6.29 ___ ___ ___ ___ unit *(DK = 9999)*

Question	Responses	(Yellow column)	(Blue column)
Did the child reach the <FIRST/LAST HEALTH PROVIDER> before s/he died? *[If "No," discuss with respondent to determine correct response: 2, 3 or 4.]*	1. Yes, reached before child died 2. No, died before setting out 3. No, died on route to this provider 4. No, could not reach this provider – did not set out/returned home/took other action 9. Don't know	S6.14.1 ☐ *2, 3 → SQ6.39* *4, 9 → Inst_4*	S6.29.1 ☐ *2-9 → SQ6.39*
How long did it take to travel to the <FIRST/LAST HEALTH PROVIDER>? *[Mark hours &/or minutes as needed: e.g. 02 hours, 10 minutes]*		S6.15 ___ ___ Hours *(DK = 99)* ___ ___ Minutes *(DK = 99)*	S6.30 ___ ___ Hours *(DK = 99)* ___ ___ Minutes *(DK = 99)*
What did the <FIRST/LAST HEALTH PROVIDER> do for <NAME>'s problem? *Prompt:* Was there anything else? *[Multiple answers allowed.]*	1. Gave oxygen .... 2. Helped breathe with bag or mask . 3. Gave fluids by mouth .... 4. Gave antibiotics by mouth............ 5. Gave antimalarial by mouth .... 6. Gave ORS................................ 7. Gave Vitamin A .... 8. Gave other medicine by mouth ..... 9. Gave IM medicine .... 10. Gave IV fluids or medicine .... 11. Advised to buy outside medicine .. 12. Did an operation *(specify)*............ 13. Admitted to hospital .... 14. Other *(specify)* .... 15. Nothing... 99. Don't know	S6.16 1. ☐ 2. ☐ 3. ☐ 4. ☐ 5. ☐ 6. ☐ 7. ☐ 8. ☐ _____ 9. ☐ 10. ☐ 11. ☐ 12. ☐ _____ 13. ☐ stayed __ __ days 14. ☐ _____ 15. ☐ → *SQ6.18* 99. ☐ → *SQ6.18*	S6.31 1. ☐ 2. ☐ 3. ☐ 4. ☐ 5. ☐ 6. ☐ 7. ☐ 8. ☐ _____ 9. ☐ 10. ☐ 11. ☐ 12. ☐ _____ 13. ☐ stayed __ __ days 14. ☐ _____ 15. ☐ → *SQ6.33* 99. ☐ → *SQ6.33*
How much did you pay for these treatments and other costs related to the health care, including the admission fee, consultation, lab tests, equipment, and room and food for companions?		S6.17 __ __ __ __ __ unit *(DK = 99999)*	S6.32 __ __ __ __ __ unit *(DK = 99999)*
Did the <FIRST/LAST HEALTH PROVIDER> refer <NAME> to another health provider or facility?	1. Yes 2. No 9. Don't know	S6.18 ☐ *2 or 9 → SQ6.19*	S6.33 ☐ *2 or 9 → SQ6.34*
Why was <NAME> referred? *[Multiple answers allowed.]*	1. The provider was not capable of managing the problem .... 2. Required supplies (e.g., drugs, IV, oxygen) not available .... 3. Required equipment (e.g., xray machine) not available .... 9. Don't know	S6.18.1 1. ☐ 2. ☐ 3. ☐ 9. ☐	S6.33.1 1. ☐ 2. ☐ 3. ☐ 9. ☐
Did <NAME> leave the <FIRST/LAST HEALTH PROVIDER> alive?	1. Yes, left alive 2. No, died at this provider	S6.19 ☐ *2 → Open History*	S6.34 ☐ *2 → Open History*
Did the <FIRST/LAST HEALTH PROVIDER> suggest that you do anything for <NAME>'s illness after leaving?	1. Yes 2. No 9. Don't know	S6.20 ☐ *2 or 9 → SQ6.22*	S6.35 ☐ *2 or 9 → SQ6.37*

Question	Choices	First (S6.20.1)	Last (S6.35.1)
What did the <FIRST/LAST HEALTH PROVIDER> suggest that you do? *Prompt:* Was there anything else? [Multiple answers allowed.]	1. Increase breastfeeding 2. Give extra fluids 3. Continue feeding 4. Give ORS 5. Give antibiotic by mouth 6. Give antimalarial by mouth 7. Give vitamin A by mouth 8. Return for follow-up visit 9. Return or referred if worse 10. Complete the present referral 11. Other (specify) 99. Don't know	S6.20.1 1. ☐ 2. ☐ 3. ☐ 4. ☐ _____ 5. ☐ 6. ☐ 7. ☐ 8. ☐ 9. ☐ 10. ☐ 11. ☐ _____ 99. ☐ → **SQ6.22**	S6.35.1 1. ☐ 2. ☐ 3. ☐ 4. ☐ _____ 5. ☐ 6. ☐ 7. ☐ 8. ☐ 9. ☐ 10. ☐ 11. ☐ _____ 99. ☐ → **SQ6.37**
Were you able to follow all the advice?	1. Yes 2. No 9. Don't know	S6.21 ☐ **9 → SQ6.22**	S6.36 ☐ **9 → SQ6.37**
If not able to follow all the advice, ask: Did you have any concerns or problems that kept you from following the advice? *If able to follow all the advice, ask:* Did you have to overcome any concerns or problems to follow the advice?	1. Yes 2. No 9. Don't know	S6.21.1 ☐ **2 or 9 → SQ6.22**	S6.36.1 ☐ **2 or 9 → SQ6.37**
What concerns or problems did you have? *Prompt:* Was there anything else? [Multiple answers allowed.]	1. Did not understand instructions 2. Too much time from regular duties 3. Someone else (specify) decided 4. Cost too much 5. Problem required traditional care 6. Thought advised care not needed 7. Thought care might harm the child 8. Thought child will die despite care 9. No time before go to next provider 10. The child died too soon 11. Other (specify) 99. Don't know	S6.21.2 1. ☐ 2. ☐ 3. ☐ _____ 4. ☐ 5. ☐ 6. ☐ 7. ☐ 8. ☐ 9. ☐ 10. ☐ 11. ☐ _____ 99. ☐	S6.36.2 1. ☐ 2. ☐ 3. ☐ _____ 4. ☐ 5. ☐ 6. ☐ 7. ☐ 8. ☐ 9. ☐ 10. ☐ 11. ☐ _____ 99. ☐

After leaving the <FIRST/LAST HEALTH PROVIDER>, was <NAME>… [Read the choices for each condition.]	Conditions	S6.22 Nrml / Med / Abnrm / DK	S6.37 Nrml / Med / Abnrm / DK
	1. Feeding normally, poorly, or not at all	1. ☐ 2. ☐ 3. ☐ 9. ☐	1. ☐ 2. ☐ 3. ☐ 9. ☐
	2. Alert, drowsy, or unconscious	1. ☐ 2. ☐ 3. ☐ 9. ☐	1. ☐ 2. ☐ 3. ☐ 9. ☐
	3. Normally active, less active than normal, or not moving	1. ☐ 2. ☐ 3. ☐ 9. ☐	1. ☐ 2. ☐ 3. ☐ 9. ☐

Inst_3: Check SQ6.5 to determine if taken to another health provider

Question	Choices	First (S6.23)	Last (S6.38)
If not taken to another health provider, ask: Did you have any concerns or problems that kept you from taking <NAME> to another health provider? *If taken to another health provider, ask:* Did you have to overcome any concerns or problems to take <NAME> to another health provider?	1. Yes 2. No 9. Don't know	S6.23 ☐ **2 or 9 → Inst_4**	S6.38 ☐ **2 or 9 → SQ6.39**

Study ID#									
	Village/Cluster			HH			Child		

**CHILD HEALTH EPIDEMIOLOGY REFERENCE GROUP
SB/NN/CHILD SOCIAL AUTOPSY QUESTIONNAIRE**

What concerns or problems did you have? *Prompt:* Was there anything else? [Multiple answers allowed.]	1. Thought no more care needed....... 2. No one available to go with her...... 3. Too much time from regular duties 4. Someone else *(specify)* decided.... 5. Too far to travel............................. 6. No transportation available .... 7. Cost (transport, health care, other) 8. Not satisfied with available care..... 9. Problem required traditional care... 10. Thought child too sick to travel .... 11. Thought child will die despite care. 12. Was late at night.......................... 13. The child died before going .... 14. Other *(specify)* .... 99. Don't know...................................	S6.23.1 1. ☐ 2. ☐ 3. ☐ 4. ☐ _____ 5. ☐ 6. ☐ 7. ☐ 8. ☐ 9. ☐ 10. ☐ 11. ☐ 12. ☐ 13. ☐ → **SQ6.39** 14. ☐ _____ 99. ☐	S6.38.1 1. ☐ 2. ☐ 3. ☐ 4. ☐ _____ 5. ☐ 6. ☐ 7. ☐ 8. ☐ 9. ☐ 10. ☐ 11. ☐ 12. ☐ 13. ☐ 14. ☐ _____ 99. ☐
Inst_4: Check SQ6.5 → If taken to another health provider…		*…go to SQ6.24 (LAST PROVIDER)*	
S6.39	How many days after (first noticing the illness / <LAST ACTION SQ6.5> / leaving the first/last health provider) did <NAME> die? [If SQ6.4 = 2 (No care given), then read: "…first noticing the illness…"]		___ ___ Days *(<1 = 00; DK = 99)*