

Household Questionnaire for assessing the knowledge, attitude and practice about sickle cell anemia in Tharu community of Kailali District			
Municipality		Ward no.	
Interview Date:		Tole	
Participant ID		Contact Number:-	

Section A:Socio-demographic information				
Q.N.	Questions	Code	Response	Remarks
A1	Date of birth (dd/mm/yyyy)		Age in completed years.....	
A2	Marital Status	1	Never Married	
		2	Currently Married	
		3	Separated or Divorced	
		4	Widowed	
A3	Which religion do you follow?	1	Hindu	
		2	Buddhist	
		3	Muslim	
		4	Christian	
		5	Others (Specify).....	
A4	What is your educational status?	1	Illiterate	
		2	Literate	
		3	Primary(1-8 grade)	
		4	Secondary(9-10 grade)	
		5	Higher Secondary(11-12 grade)	
		6	Bachelor and above	
A5	What is your employment status?	1	Homemaker	
		2	Agriculture	
		3	Labor	
		4	Business	
		5	Government Services	
		6	Private sector	
		7	Student	
		8	Foreign employee	
		9	Others (Specify).....	
A6	Type of Family?	1	Nuclear	
		2	Joint	
		3	Extended	

A7	Household average monthly income		NPR.	
A8	Is your family enrolled in the national health insurance scheme?	1	Yes	
		2	No	

Section B: Knowledge about sickle cell anemia				
	General Information about disease			Remarks
Q.N	Questions	Code	Response	
B1	Have you heard about sickle cell anemia, which is prevalent in The Tharu community in Nepal?	1	Yes	
		2	No	If No, go to B3
B2	If Yes, through which channel?	1	Radio	
		2	Television	
		3	FCHV	
		4	Health Person	
		5	Family member	
		6	Online social media	
		7	Other, mention....	
B3	What type of disease is sickle cell anemia?	1	Hereditary	
		2	Non-hereditary	
		3	Don't know	
B4	Can sickle cell anemia be completely cured?	1	Yes	
		2	No	
		3	Don't know	
B5	If both parents are sickle cell positive, is there any probability of having SCD in child?	1	Yes	
		2	No	
		3	Don't know	
B6	If both parents are carrier or trait, is there any probability of having SCD in children?	1	Yes	
		2	No	
		3	Don't know	
B7	If only one of the parent has SCD/SCD CT, is there any chances of being SCD in children?	1	Yes	
		2	No	
B8	Can sickle cell anemia be prevented from passing from one generation to the next?	1	Yes	
		2	No	
		3	Don't know	

Clinical signs, diagnosis and treatment for sickle cell disease.

B9	What are the main symptoms of sickle cell anemia?	Yes	No	Don't know	Remarks
		1	2	3	
	a. Painful swelling of hands and feet				
	b. Anemia				
	c. Dark Urine				
	d. Yellow eyes				
	e. Stunted growth				
	f. Severe tiredness				
	g. Recurrent infection				
	h. Haepatomegaly / Spleenomegaly				
	i. Stroke				
B10	Where is sickle cell anemia diagnosis and treatment service available?	1	HP/BHC/CHU		
		2	PHC		
		3	District Hospital and above level hospital		
		4	Other, mention....		
		5	Don't know		
B11	How Sickle cell disease is diagnosed?	1	Blood		
		2	Urine		
		3	Other		
		4	Don't know		
B12	Do you know that people with sickle cell anemia need to take more precautions than others to stay healthy?	1	Yes		
		2	No		
		3	Don't know		
B13	Do you know that people with sickle cell anemia should take regular medications for the disease?	1	Yes		
		2	No		
		3	Don't know		
B14	Do you know that sickle cell anemia affected person often get sickle cell anemia crisis or complication	1	Yes		
		2	No		
		3	Don't know		

Section C: Attitude about Sickle cell Anemia

Q.N	Response		Strongly agree	Agree	Neutral	disagree	Strongly disagree	Remarks
	Questions	Code	1	2	3	4	5	
C1	It is necessary to know the status of your partner regarding sickle cell anemia.							
C2	Sickle cell anemia status influence your choice of sexual partner							
C3	Are you ready to marry a sickle cell affected person?							
C4	Are you willing to marry a carrier partner despite knowing the risk of SCD births?							
C5	Sickle cell disease is a curse of God							
C6	Only poor people suffer from SCD/SCT.							
C7	Sickle cell disease, being a genetically transmitted disorder, cannot be prevented.							
C8	There is a need to take regular treatment for sickle cell disease.							
C9	There is a need for premarital screening of a spouse for SCT/SCD.							
C10	Prenatal diagnosis is necessary to prevent SCT/SCD.							
C11	All children should be screened for SCT/SCD.							

D. Preventive Practice about sickle cell anemia

Q.N.	Questions	Code	Response	Remarks
D1	Have you been tested for sickle cell anemia?	1	Yes	
		2	No	If No, go To D3
D2	If yes, When you did sickle cell Anemia testing?	1	Before marriage	
		2	After marriage	
		3	During pregnancy(female)	
		4	After child birth(female)	
D2.1	If yes, what was the result?	1	Positive	
		2	Carrier or trait	
		3	Negative	If Negative, go to D3
D2.2	If positive, Have you regularly taking medicine?	1	Yes	
		2	No	
D2.3	If positive, Have you regularly taking special precaution to prevent the complication?	1	Yes	
		2	No	
D3	Have you tested your partner for sickle cell anemia?	1	Yes	
		2	No	If No, go to D4
		3	N/A	If N/A, go to D5
D3.1	If yes, what was the result?	1	Positive	
		2	Carrier or trait	
		3	Negative	If negative, go to D4
D3.2	if positive, Have your partner regularly taking medicine?	1	Yes	
		2	No	
D3.3	If positive, Have your partner regularly taking special precaution to prevent the complication?	1	Yes	
		2	No	
D4	Have you tested your children for sickle cell disease diagnosis?	1	Yes	
		2	No	If No, go to D5
		3	N/A	If N/A, got to D5
D4.1	If yes, what was the result?	1	Positive	
		2	Carrier or trait	
		3	Negative	If Negative, go to D5
D4.2	If positive, Have your child regularly taking medicine?	1	Yes	
		2	No	

D4.3	If positive, Have your child regularly taking special precaution to prevent the complication?	1	Yes	
		2	No	
D5	Do you advice other people to go for screening of sickle cell anemia	1	Yes	
		2	No	