

IEC & Stigma Reduction Questionnaire

The effectiveness of Information Education and Communication (IEC) interventions in reducing stigma among Sickle Cell Disease patients in Alebtong district, Uganda

Informed Consent

Hello madam/sir, my name is We are conducting a study on stigma among sickle cell disease patients in this community. The purpose of this study is to zexamine the effectiveness of Information Education and Communication (IEC) interventions in reducing stigma among Sickle Cell Disease patients. The information collected will be used to make recommendations that will guide policy making and improve interventions **among sickle cell patients**. We would very much appreciate your participation. Participation in the study is voluntary and you can stop the interview at any time you feel like. The information got will be strictly kept confidential and will only be used for academic purposes. The interview will last 30 minutes.

Do you have any questions that you would like to ask?

May I begin the interview now? 1 - Yes 2 – No (*Tick appropriate response*) **End the interview**

IDENTIFICATION

Date of interview.....

Sub-county & code.....

Parish & code

LC1/Village & code

Interviewer Name & Code.....

Number of Interview.....1st time/ 2nd time/ 3rd time

SECTION 1: RESPONDENT'S BACKGROUND

No.	Questions	Responses	Skip
101x.	Unique Respondent ID		
101a.	How old are you? (Age in complete years)		
101b	Date of birth		
102	Sex	Male.....1 Female.....2	
102.	What is the highest level of education attained?	None.....1 Incomplete Primary.....2 Complete Primary.....3 Incomplete Secondary.....4 Complete Secondary.....5 Post-secondary.....6	
103.	Place of residence	Rural.....1 Urban.....2	
104.	What is your religion?	Catholic.....1 Protestant/ Anglican.....2	

		Pentecostal/ Born Again.....3 Muslim.....4 SDAs.....5 None.....6 Others (specify).....7											
105.	What is your tribe?	Langi.....1 Itesot.....2 Kumam.....3 Karamajong.....5 Other (Specify).....6											
106.	What is your occupation?	Peasant Farmer.....1 Trader.....2 Housewife.....3 Unemployed.....4 Professional.....5 Businesswoman.....6 Hair Dresser.....7 Tailor.....8 Shopkeeper.....9 Others (Specify).....99											
107.	What is your current marital status?	Single.....1 Married2 Living Together.....3 Widowed.....4 Divorced/Separated.....5	109										
108.	What is your partner’s education level?	None.....1 Incomplete Primary.....2 Complete Primary.....3 Incomplete Secondary.....4 Complete Secondary.....5 Tertiary.....6 Don’t know.....7											
109.	Does your household own the following items? a. Radio b. Television c. Mobile telephone d. Electricity e. Solar	<table><tr><td>Yes</td><td>No</td></tr><tr><td>1</td><td>2</td></tr><tr><td>1</td><td>2</td></tr><tr><td>1</td><td>2</td></tr><tr><td>1</td><td>2</td></tr></table>	Yes	No	1	2	1	2	1	2	1	2	
Yes	No												
1	2												
1	2												
1	2												
1	2												
110.	Do you read a newspaper or magazine at least once a week, less than once a week or not at all?	Almost every day.....1 At least once a week.....2 Less than once a week.....3 Not at all.....4											
111.	Do you listen to the radio at least once a week, less than once a week or not at all?	Almost every day.....1 At least once a week.....2 Less than once a week.....3 Not at all.....4											
112.	Do you watch television at least once a week, less than once a week or not	Almost every day.....1 At least once a week.....2											

	at all?	Less than once a week.....3 Not at all.....4	
113.	What is the main or commonest channel through which you receive your information?	Radio.....1 Community announcer.....2 Television.....3 Internet/Telephone.....4 Newspapers.....5 Word of mouth.....6 Other (Specify).....7	
114.	What is the main or commonest channel through which you receive health information?	Radio.....1 Community announcer.....2 Television.....3 Internet/Telephone.....4 Newspapers.....5 Health providers.....6 VHTs.....7 Other (Specify).....8	
115.	What is the main source of drinking water for this household?	Piped water.....1 Spring.....2 Borehole.....3 Open well.....4 River/stream/Pond/lake/dam.5 Rain water 6 Bottled water 7 Other (specify).....8	
116.	Do you do anything to the water to make it safer to drink?	Yes.....1 No.....2	→ 118
117.	What do you usually do to make the water safer to drink? Anything else? RECORD ALL MENTIONED.	Boil..... A Add water guard.....B Add bleach/chlorine.....C Strain through a cloth..... D Use water filter (Ceramic/ sand/composite/ETC.....E Solar disinfection.....F Let it stand and settle.....G Others (Specify).....H	
118.	What is the distance to the nearest health facility	<5kms.....1 5-10kms.....2 >10kms.....3	
119.	Does your household have any mosquito nets that can be used while sleeping?	Yes.....1 No.....2	→ 201
120.	How many mosquito nets does your household have?	_____	
SECTION 2: Knowledge of sickle cell disease Now I would like to ask you some questions about Sickle Cell Disease.			
201.	Have you ever heard of sickle cell disease?	Yes.....1 No.....2	→ END

202.	What was the source of information about sickle cell disease (Multiple choice)	Radio.....A Television.....B Newspapers.....C Health workers/health education....D Community health workers/VHTs...E Community outreach/seminars.....F School.....G Peers/community/neighbours.....H Internet.....I Literature.....J Affected persons.....K Friends.....L Family.....L Others (Specify).....M	
203.	Do you know someone who has sickle cell disease?	Yes.....1 No.....2	→205
204a.	Is the person who has SCD your family member/relative/ friend?	Immediate family.....1 Other family.....2 Neighbour/ friend.....3	→205
204b.	If relative / family member, specify the relationship	Parent1 Parent-in-law2 Wife or husband3 Son or daughter.....4 Son or daughter-in-law.....5 Other relative6 Don't know7	
205	Do you know the signs and symptoms of sickle cell disease	Yes.....1 No.....2	207
206	Which signs and symptoms of sickle cell disease do you know about?	AnaemiaA Yellow eyes.....B Pain crisis.....C Swollen Limbs.....D Frequent illnessE Stunted growthF Others specify.....G	
207.	How does a person get sickle cell disease?	Hereditary.....1 It's a curse from God.....2 Adultery.....3 Witchcraft.....4 Sexually transmitted.....5 Infectious just like cough & flu.....6 Marry close relative.....7 Others (specify).....7	
208.	Can people get sickle cell disease from witchcraft or other supernatural	Yes.....1 No.....2 Not sure/Don't know.....3	

	means?		
209.	Can children get sickle cell disease from parents/ mother?	Yes.....1 No.....2 Don't know/Not sure.....3	
210.	Can a healthy looking person have sickle cell disease?	Yes.....1 No.....2 Don't Know/Not sure.....8	
211.	Do you think SCD testing reduces the transmission of SCD from parents to children	Yes.....1 No.....2 Don't Know.....8	
212.	How is sickle cell disease tested?	Blood test.....1 Urine test.....2 It's impossible to test.....3 Others specify.....4 Don't Know.....8	
213.	Do you think you are at risk of having children with sickle cell disease	Yes.....1 No.....2 Don't know.....8	→ 214b → 215
214a.	Why do you think you are at risk of having children with SCD?	I have/spouse has SCD.....1 I have relatives with SCD.....2 Others specify.....3	
214b.	Why do you think you are not at risk of having children with SCD?	I don't/spouse doesn't have SCD....1 I believe in God.....2 I have charms to protect me.....3 Others specify.....4	
215.	What are the chances of having children with SCD when both parents have no SC trait/ are normal?	No chance.....0 Some chance1 Don't know.....8	
216.	What are the chances of having children with SCD when both parents have SCD?	No chance.....0 Some chance1 Don't know.....8	
217.	What are the chances of having children with SCD when both parents have SC trait?	No chance.....0 Some chance1 Don't know.....8	
218.	What are the chances of having children with SCD when one of the parents has SC trait and the other parent has no SCD?	No chance.....0 Some chance1 Don't know.....8	
219.	What are the chances of having children with SCD when one of the parents has SC trait and the other parent has SCD?	No chance.....0 Some chance1 Don't know.....8	
220.	What are the chances of having children with SCD when one of the parents is normal (no SC trait) and the other parent has SCD?	No chance.....0 Some chance1 Don't know.....8	

221.	Do religious institutions ask for sickle cell test results before marriage?	Yes.....1 No.....2 Don't know.....8	
222.	Do you know any medication for persons with SCD?	Yes.....1 No.....2	→ 224
223.	Which medication for SCD do you know of?	Blood transfusion.....A Modern medicine.....B Herbal medication.....C Witchcraft.....D Don't Know.....E Others (specify).....F	→ 224
223a	Which medication for SCD is preferred?	Modern medicine.....1 Herbal medication.....2	
223b	Why is 1 or 2 preferred?	Costs1 Accessibility.....2 Effectiveness3 Fewer side effects4 Recommendation5 Others (specify).....6	
224.	Are there health facilities in this district that provide SCD care or services	Yes.....1 No.....2 Don't know.....8	} 226
225	Which health facilities provide SCD care/services? (Multiple choice:	Alebtong HC IV.....A Abia HC III.....B Adwir HC III.....C Amogo HC III.....D Abako HC III.....E Akola.....F Private health facility.....G Others specify.....H	
226.	Which SCD related services do these health facilities provide?	TestingA Counselling.....B Blood transfusion.....C Pain relievers.....D Other medicine.....E Hydroxyurea.....F Others (specify).....G	
227	Do you know any home based care practices for management of SCD?? (Multiple choice)	Drink plenty of water.....A Keep warm.....B Avoid extreme weather conditions...C Eat a balanced diet.....D Have regular medical examinations..E Take your medicine as prescribed....F Others specify.....G	
228.	Have you ever heard of/ Are there organisations that support SCD	Yes.....1 No.....2	→230

	patients in your community?		
229.	Which organisations?		
230.	Have you ever participated in community activities that concern SCD?	Yes.....1 No.....2	→ 301
230b.	Which activities have you participated in?		
SECTION 3: Attitudes towards SCD patients and SCD carriers/ SCD practices			
301.	Have you ever tested for SCD	Yes.....1 No.....2	→ 307
302.	Why did you take the SCD test?	Voluntary/Premarital/genetic screening.....1 Premarital requirement.....2 Was trying to have a child.....3 SC trait runs in my family.....4 Medical requirement.....5 Job requirement.....6 Research purposes.....7 It was offered.....8 Others (Specify).....9	
303	Where did you take the SCD test from?	Health Facility.....1 Community outreach.....2	
304	Did you get your SCD test results?	Yes.....1 No.....2	→ 310
305.	Do you know your SCD status/genotype?	Yes.....1 No.....2	→ 309
306.	If yes, what is your SCD status/genotype	AA.....1 AS.....2 SS.....3 Don't Know4	308 → 307
307.	Why have you never had a sickle cell test?	Not at risk of SCD.....1 Did not know/Not aware.....2 Not offered at the health facility.....3 Expensive.....4 Others (specify).....5	
308.	Have you ever been offered a sickle cell test	Yes.....1 No.....2	→ 310
309.	If offered a SCD test, would you be willing to test?	Willing to test.....1 Not willing to test.....2 Not sure.....3	
310.	How do you feel about people/children who have SCD? (Multiple choice)	Sympathetic.....A Depressed.....B Embarrassed.....C Do not care.....D Worry less since they will die soon....E Angry.....F	

		Scary/FrighteningG Others (specify).....H	
311.	Do you think everyone should know their SCD status/Genotype?	Yes.....1 No.....2 Not sure.....3	
312.	If married/living together , do you know your partners SCD status/genotype?	Yes.....1 No.....2	
313.	If married/ Check question 107 , Did you have a SCD test before you married	Yes.....1 No.....2	
314.	If married or have ever had children , was SCD status among the factors for choosing a partner?	Yes.....1 No.....2	
315.	If married , was SCD test a requirement in church/mosque/place of worship before you were wedded	Yes.....1 No.....2	
316.	If not married , would you marry someone with SCD / a carrier?	Yes.....1 No.....2 Not sure.....3	
317.	What should be done by a couple when they discover that their genotype predisposes them to having children with SCD?	Discontinue their relationship.....1 Continue with their relationship and live with the consequences.....2 Seek genetic counselling and make informed consent.....3 Don't know.....4 Others specify.....5	
318.	Would you be worried, caring for a person with SCD?	Yes No Don't Know 1 0 8	
319.	Do you think SCD patients die young?	Yes No Don't Know 1 0 8	
320.	Do you think children with SCD should socialise/play with other children?	Yes No Don't Know 1 0 8	
321.	Do you think children with SCD should go to school?	Yes No Don't Know 1 0 8	
322.	Do you think persons with SCD should marry?	Yes No Don't Know 1 0 8	
323.	Do you think persons with SC trait should marry?	Yes No Don't Know 1 0 8	
324.	Do you think persons with SCD/SC trait should have children?	Yes No Don't Know 1 0 8	
325.	Do you think someone with SCD should work?	Yes.....1 No.....2 Don't know.....3	→ 327 → 327
326.	If no, why shouldn't persons with SCD work	They are weak.....1 Fall sick more often.....2 They are scary/frightening.....3	

		They can transmit the disease to others.4 Others (Specify).....5	
327.	Do people in the community talk badly about individuals with SCD?	Yes.....1 No.....2 Don't know /Not sure.....3	
328.	Do individuals with SCD lose the respect of other people in the community	Yes.....1 No.....2 Don't know /Not sure.....3	
329.	What do community members say about persons with SCD?		
330.	Do you agree with the statement: I would be ashamed if someone in my family has SCD?	Yes.....1 No.....2 Don't know /Not sure.....3	
331.	Is divorcing/separating with a partner with SCD justified?	Yes.....1 No.....2 Don't know /Not sure.....3	
332.	Has government done anything to help persons with SCD in this community?	Yes.....1 No.....2→	334
333.	What has government done to help people with SCD in this community?		
334.	Do you think local leaders have done enough to help persons/patients with SCD	Yes.....1 No.....2→	336
335	What have local leaders done to help persons/patients with SCD?		
336.	How can we stop sickle cell disease? (Multiple response)	Genetic counselling.....A Premarital screening.....B Marrying people with no SCD.....C Nothing can be done.....D Others (Specify).....E	
337.	What can be done to improve the lives of persons with SCD?		
	Any comment or observation?		

THANK YOU