

Questionnaire: Examining Barriers to Service Access and Diabetes co-morbidity among TB patients in the Democratic Republic of Congo

Survey A – Listing of eligible patients at the TB Diagnosis and Treatment Center			
This section is to be filled out at the health facility by a member of the study team with the aid of the healthcare team in order to list eligible participants affiliated to the facility.			
#	Question	Response Options	Skip Pattern, Constraints
A1	Province	1 = Kasi Oriental 2 = Lomami 3 = Tanganyika 4 = Sud Kivu	
A2	Strata	1 = Rural 2 = Urban	
A3	ID of the health facility	1 = [Health Facility A] 2 = [Health Facility B] 3 = [Health Facility C] 4 = etc...	
A4	Patient ID: (Taken from patient records)	[text entry]	
A5	Does the patient have a laboratory confirmed diagnosis of pulmonary tuberculosis?	0 = No 1 = Yes	If [0] patient is ineligible.
A6	Date of current tuberculosis diagnosis: (DD/MM/YYYY)	[date entry]	If [date] is outside of the 6 month criteria, then the patient is ineligible to participate.
A7	Patient age: (years)	[numeric entry]	If [<18] patient is ineligible. Constraint: [>=0]

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Survey B: Sociodemographics; Glucose blood test; Knowledge and attitudes toward TB treatment

Section: Consent and Screening Questions

This section is to be filled out by the data collector with the respondent. The respondent's clinical data should have been previously recorded using Survey A.

#	Question	Response Options	Skip Pattern, Constraints
S1	today	ODK field	
S2	start	ODK field	
S3	end	ODK field	
S4	deviceid	ODK field	
S5	Data collector's name/ID number:	1 = [Enumerator A] 2 = [Enumerator B] 3 = [Enumerator C] 4 = etc.	
S6	Patient ID (Note: Manually enter the respondent's Patient ID used in Survey A)	[text entry]	These questions need to be programmed using dynamic linking for KoboToolbox between Survey A and Survey B. Once the Patient ID is manually entered, Kobo will automatically pull the data for these questions from Survey A.
S7	Province where respondent lives:	ODK field: Automatically Pulled from Survey A	
S8	Strata where the respondent lives:	ODK field: Automatically Pulled from Survey A	
S9	ID of the health facility where the respondent receives care:	ODK field: Automatically Pulled from Survey A	
S10	Does the patient have a laboratory confirmed diagnosis of pulmonary tuberculosis?	ODK field: Automatically Pulled from Survey A	
S11	Date of current tuberculosis diagnosis: (DD/MM/YYYY)	ODK field: Automatically Pulled from Survey A	
S12	Patient age: (years)	ODK field: Automatically Pulled from Survey A	
S12	How old are you? (years)	[numeric entry]	If [<18] patient is ineligible. Constraint: [>=0]
S13	When did you have you last meal, snack, or drink other than water?	1 = Less than 8 hours ago 2 = More than 8 hours ago	If [1] continue to S14 If [2] skip to S15

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S14	To participate in this study, you should fast for at least 8 hours to undergo a blood glucose test. This means you should not eat or drink anything besides water for at least 8 hours before you can participate. Are you willing to fast for 8 hours?	0 = No 1 = Yes	If [0] skip to EN1 If [1] skip to EN2
S15	Take respondent through the informed consent process and ask if they understand the purpose of the study, if they have questions, and if they consent to participate.	0 = No, respondent does not consent. 1 = Yes, respondent gives consent and has been given the opportunity to ask questions.	If [0] skip to EN1 If [1] continue to Section 1
S16	Do you consent for the study team to discuss his/her tuberculosis care with the provider?	0 = No 1 = Yes	
EN1	Thank the respondent and end the survey. They are not eligible to participate.		
EN2	Instruct the respondent to fast for 8 hours and schedule a time to come back the next day before the respondent ends their fast.		

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Section 1: Blood Glucose Level and Demographics			
Section Relevance: S13 = 2 and S15 = 1			
#	Question	Response Options	Skip Pattern, Constraints
EN3	"I will first measure your fasting blood glucose level, then ask you questions about yourself, marital status, education, employment, and other general and household information."		
EN4	Take the respondent's fasting blood glucose level. Be sure to strictly adhere to the instructions provided to you, as well as safety and hygiene guidance.		
Q	Study ID: Concatenate: Province ID – Strata ID – Health Facility ID – Data Collector ID – Respondent number	[Manual entry / ODK field]	
Q	Fasting blood glucose level:	[numeric entry]	Units: mg/dL
Q1.1	What is your sex?	1 = Male 2 = Female 997 = Other 999 = Prefer to not answer	
Q1.2	What is your marital status?	1 = Single/never married 2 = Partnered, but not married 3 = Married 4 = Divorced/Widowed 999 = Prefer to not answer	
Q1.3	What is your highest level of education attained?	1 = Primary or less 2 = Secondary 3 = University 4 = Technical/vocational 997 = Other 998 = Don't know 999 = Prefer to not answer	
Q1.4	Do you live in the health zone where this facility or the facility you last used to get TB care is located?	0 = No 1 = Yes 998 = Don't know	
Q1.5	What is your employment status?	1 = Regular full-time employment 2 = Regular part-time employment 3 = Self-employed 4 = Contracted/temporary work or labor 5 = Student 6 = Unemployed	

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		997 = Other 998 = Don't know 999 = Prefer to not answer	
Q1.6	What is your religious affiliation?	1 = Catholic 2 = Protestant 3 = Evangelical/Pentecostal 4 = Muslim 5 = Kimbanguist 6 = No religion 997 = Other 999 = Prefer to not answer	
Q1.7	What is your monthly income?	1 = No income/Not applicable 2 = ≤ 60 USD 3 = 61 – 100 USD 4 = 101 – 200 USD 5 = 200 – 500 USD 6 = 501 – 1000 USD 7 = ≥ 1001 USD 998 = Don't know 999 = Prefer to not answer	
Q1.8	Do you or anyone in your household own animals/livestock?	0 = No 1 = Yes 999 = Prefer to not answer	If [0] skip to Q1.10
Q1.9	How many total animals/livestock do you own? (number of animals)	[numeric entry] Enter <u>999</u> to <i>Prefer to not answer</i>	Constraint: [≥0]
Q1.10	Do you or anyone in your household own: <i>Read off the list, allowing the respondent to answer no or yes.</i>	Mark <u>0</u> for <i>No</i> , and <u>1</u> for <i>Yes</i> Enter <u>998</u> if <i>Don't know</i> Enter <u>999</u> if <i>Prefer to not answer</i> ☐ Electricity ☐ Radio ☐ Television ☐ Mobile phone ☐ Regular/non-mobile phone ☐ Refrigerator ☐ Air conditioning or heating ☐ Watch ☐ Bicycle ☐ Car, truck, vehicle ☐ Moto, scooter ☐ Boat with motor ☐ Animal-drawn cart	
Q1.11	Do you or anyone in your household own land for agriculture or farming?	0 = No 1 = Yes 998 = Don't know 999 = Prefer to not answer	If [0] skip to Q1.13

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Q1.12	How many hectares of land do you own?	[numeric entry] Enter <u>00</u> if less than 1 hectare Enter <u>999</u> for <i>Prefer to not answer</i>	
Q1.13	Do you or anyone in your household have a bank account?	0 = No 1 = Yes 998 = Don't know 999 = Prefer to not answer	

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Section 2: Medical History			
#	Question	Response Options	Skip Pattern, Constraints
Q2.1	Have you ever been diagnosed with tuberculosis in the past?	0 = No 1 = Yes 998 = Don't know/Don't remember 999 = Prefer to not answer	If [0] skip to Q2.7
Q2.2	Not including the current infection, how many times have you ever been diagnosed with tuberculosis?	[numeric entry]	Constraint: [≥0]
Q2.3	When was your first diagnosis of tuberculosis? (MM/YYYY)	[date entry] Enter 01/1900 if don't know/don't remember	
Q2.4	When was the most recent diagnosis of tuberculosis? (MM/YYYY) <i>"Most recent" refers to the diagnosis before the current one.</i>	[date entry] Enter 01/1900 if don't know/don't remember	
Q2.5	When is the last time/most recent date you went to the health facility to receive care or treatment for tuberculosis? (MM/YYYY)	[date entry] Enter 01/1900 if don't know/don't remember	
Q2.6	How many people live in your household?	[numeric entry] Enter <u>999</u> for Prefer to not answer	
Q2.7	How many people in your household have ever been diagnosed with tuberculosis?	[numeric entry] Enter <u>999</u> for Prefer to not answer	Constraint: [≥0 and ≤ Q2.6]
Q2.8	Have you ever been diagnosed with diabetes?	1 = Yes, I did a test 2 = Yes, I did not do a test 3 = No, I did a test 4 = No, I have never been tested 998 = Don't know 999 = Prefer to not answer	If [3] or [4] or [5] or [999] skip to Q2.11
Q2.9	When was the diabetes diagnosis made? (MM/YYYY)	[date entry] Enter <u>998</u> if don't know/don't remember.	
Q2.10	Are you currently receiving treatment for diabetes?	0 = No 1 = Yes 999 = Prefer to not answer	
Q2.11	How many people in your immediate and extended family are known to have diabetes?	[numeric entry] Enter <u>998</u> for <i>Don't know</i> Enter <u>999</u> for <i>Prefer to not answer</i>	Constraint: [≥0]
Q2.12	What is your HIV status?	1 = HIV negative 2 = HIV positive	

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		998 = Don't know 999 = Prefer to not answer	
Q2.13	Have you ever been diagnosed with hypertension?	0 = No 1 = Yes 998 = Don't know 999 = Prefer to not answer	
Q2.14	Have you ever been diagnosed any/other chronic disease(s)?	0 = No 1 = Yes 998 = Don't know 999 = Prefer to not answer	If [0] skip to Q2.16
Q2.15	Please specify the chronic diseases you have been diagnosed with:	[text entry] Enter <u>999</u> for <i>Prefer to not answer</i>	
Q2.16	Do you smoke?	0 = No 1 = Yes 999 = Prefer to not answer	If [0] skip to Q2.18
Q2.17	How many cigarettes do you smoke per day on average?	[numeric entry]	Constraint: [>0]
Q2.18	Do you drink alcohol?	0 = No 1 = Yes 999 = Prefer to not answer	If [0] continue to Q2.20
Q2.19	How many days per week do you drink alcohol?	[numeric entry]	Constraint: [<=7]
Q2.20	On a typical drinking day, how many alcoholic drinks do you have?	[numeric entry] Units: 1 = Small bottle (~350 cl) 2 = Regular bottle (~720 cl) 3 = Sachet of whiskey/spirits 4 = small bottle of whiskey or other spirits 5 = Glass/cup of other alcoholic drinks.	

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Section 3: Tuberculosis Knowledge and Attitudes			
EN	"For this section, I will ask questions about tuberculosis care and treatment. Please answer the questions to the best of your knowledge. It is okay if you do not know the answer to a question."		
#	Question	Response Options	Skip Pattern, Constraints
Q3.1	Do you know what causes tuberculosis? Select only one option	1 = Germ/bacteria 2 = Virus 3 = Cold wind 4 = Smoking 5 = Spoiled soil (soil with bad odor) 6 = Poor hygiene 7 = Alcohol 9 = Inherited 998 = Don't know 999 = Prefer to not answer	
Q3.2	What is the common site for tuberculosis infection in the body?	1 = Lungs 2 = Glands 3 = Brain 4 = Bones 5 = Heart 997 = Other, please specify 998 = Don't know 999 = Prefer to not answer	If [997] continue to Q3.2_other
Q3.2_other	Please specify the site of a tuberculosis infection in the body.	[text entry]	
Tuberculosis Transmission			
EN5	"I will read several statements to you. To the best of your knowledge, please tell me if the statement is true or false."		
Q3.3	Tuberculosis is spread from person to person through the air from coughing or sneezing.	0 = False 1 = True	
Q3.4	Tuberculosis can be transmitted by sharing utensils.	0 = False 1 = True	
Q3.5	Tuberculosis can be transmitted through food.	0 = False 1 = True	
Q3.6	Tuberculosis can be transmitted through sexual contact.	0 = False 1 = True	
Tuberculosis Treatment			
Q3.7	Tuberculosis testing is available for free in the DRC.	0 = False 1 = True	
Q3.8	Tuberculosis treatment is available for free in the DRC.	0 = False 1 = True	

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Q3.9	Tuberculosis is curable.	0 = False 1 = True	
Q3.10	People with tuberculosis have the right to access health care like any other patient	0 = False 1 = True	
	Tuberculosis Symptoms		
Q3.11	Which of the following are symptoms that someone with tuberculosis might have? <i>Read off the list, allowing the respondent to answer true or false.</i>	Mark 0 for False, and 1 for True Constraint [select multiple] ☐ Cough that lasts more than 2 weeks ☐ Persistent fever ☐ Night sweats ☐ Weight loss ☐ Chest or back pain	
	Tuberculosis Attitudes and Practices		
Q3.12	In your opinion, is tuberculosis not very serious; somewhat serious; or very serious?	1 = Not very serious 2 = Somewhat serious 3 = Very serious 998 = Don't know	
Q3.13	Did you keep your tuberculosis diagnosis secret from your family members or friends? <i>If respondent has had multiple diagnoses of tuberculosis, please specify if they have kept at least one diagnosis a secret or none at all.</i>	<u>IF ONLY ONE DIAGNOSIS</u> 0 = No 1 = Yes <u>IF MULTIPLE DIAGNOSES</u> 2 = No, I have not kept any diagnoses a secret. 3 = Yes, I have kept at least one diagnosis a secret. 998 = Don't know/can't remember 999 = Prefer to not answer	
Q3.14	Would you be willing to work with someone who was previously treated for tuberculosis?	0 = No 1 = Yes 999 = Prefer to not answer	
EN6	For the following questions, if the respondent has had more than one episode of tuberculosis, please ask s/he to only consider the current episode.		
Q3.15	Where did you go first to get advice or help when you started developing tuberculosis symptoms?	1 = Health facility 2 = Religious leader (e.g., pastor, priest, imam) 3 = Traditional healer	If [997] continue to Q3.22 Constraint: [select one]

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		4 = Self-medication received from pharmacy 5 = Self-medication received from other source 997 = Other, please specify 999 = Prefer to not answer	
Q3.15_other	Please specify where you went to get advice or help:	[text entry]	
Q3.16	Why did you decide to go to the health facility after you first developed symptoms of tuberculosis?	1 = The current treatment/care I was on did not work 2 = The symptoms lasted for 3-4 weeks without getting better 3 = I realized that my symptoms might be related to tuberculosis 4 = I was told to go to the health facility 5 = My health was becoming worse 997 = Other, please specify 999 = Prefer to not answer	If [997] continue to Q3.16_other
Q3.16_other	Please specify why you decided to go to the health facility:	[text entry]	
Q3.17	How often do you go to the health facility to get tuberculosis medication?	1 = Every day or almost every day 2 = Once a week 3 = Once a twice a month 4 = Once every few months 5 = Never 999 = Prefer to not answer	If [>1] continue to Q3.19
Q3.18	Do you receive several doses of TB medication to take at home when you visit the health facility?	0 = No 1 = Yes 990 = Prefer not to answer	
Q3.19	How often do you take your tuberculosis medications?	1 = Less than once per day 2 = Once per day 3 = More than once per day 998 = Don't know 999 = Prefer to not answer	
Q3.20	If you had health problems while on tuberculosis treatment, where would you seek help?	1 = Health facility or CHW 2 = Religious leader 3 = Pharmacy 4 = Traditional healer 5 = Internet/media 6 = Family/friends 997 = Other, please specify 998 = Don't know 999 = Prefer to not answer	If [997] continue to Q3.20_other Constraint [select multiple]
Q3.20_other	Please specify where you would seek help:	[text entry]	

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Section 4: Barriers to Access			
#	Question	Response Options	Skip Pattern, Constraints
EN	“The last section will ask questions about your experiences in visiting the health facility to get care and treatment for tuberculosis.”		
	Accessing Care for Symptoms		
Q4.1	How soon after you started experiencing the first tuberculosis symptoms did you visit a health facility for these symptoms?	1 = Immediately, the same day 2 = Within the same week 3 = After a week, but less than a month 4 = 1-2 months after 5 = More than 2 months after 998 = Don't know 999 = Prefer to not answer	
EN7	“For this next question, I will ask about what happened before you sought any care or treatment for tuberculosis symptoms. I will then read off a list of potential challenges you may have experienced. Please respond ‘True’ or ‘False’ if you experienced any of them.”		
Q4.2	Before I sought help for the tuberculosis symptoms: <i>Read off the list of options, allowing the respondent to answer if the statement is true or false of their experience.</i>	Mark <u>0</u> for <i>False</i>, and <u>1</u> for <i>True</i> Constraint [select multiple] Constraint [Randomize order of response options] ☐ I did not know what to do or where to go ☐ I thought people with tuberculosis were not welcome at health facilities ☐ I did not think the symptoms needed care or treatment ☐ I thought the services were too expensive ☐ I did not have money for transportation or other costs ☐ The health center was too far ☐ I did not have time ☐ I needed permission from family members, friends, religious leaders, or others in the community ☐ I tried to self-medicate or get treated by a traditional healer ☐ I did not trust the health facility/health provider ☐ I was concerned with lack of privacy/confidentiality ☐ I worried about being evicted if my landlord found out ☐ I feared being stigmatized or abandoned by friends, family, church or other community members	

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		☐ I was not able to take off work, or did not have time to leave my responsibilities ☐ I thought or heard that medication was not available at the health facility ☐ Tests were not available at the health facility ☐ Other, specify	
Q4.2_other	Please specify:	[text entry]	
	Accessing Testing/Diagnostic Services		
Q4.3	When you first saw a provider who thought you might have tuberculosis, how soon afterwards did you go to a lab to get tested or provide a sample of saliva to get tested?	1 = Immediately, the same day 2 = Within the same week 3 = After a week, but less than a month 4 = 1-2 months after 5 = More than 2 months after 998 = Don't know 999 = Prefer to not answer	
EN8	"Now, let's talk about what happened around the time you went to get tested for tuberculosis at a lab. I will ask about potential challenges you may have experienced in going to get tested. Please respond 'True' or 'False' if you experienced any of them."		
Q4.4	Before I went to get tested for tuberculosis: <i>Read off the list of options, allowing the respondent to answer if the statement is true or false of their experience.</i>	Mark <u>0</u> for False, and <u>1</u> for True Constraint [select multiple] Constraint [Randomize order of response options] ☐ I did not know what to do or where to go ☐ I thought the lab test were too expensive ☐ I did not have money for transportation or other costs ☐ The lab was too far ☐ I did not have time ☐ I needed permission from family members, friends, religious leaders, or others in the community ☐ I did not trust the health facility/health provider who referred me to that lab ☐ I did not trust the lab ☐ I was concerned with lack of privacy/confidentiality at the lab ☐ the lab staff was not supportive or professional ☐ I feared being stigmatized or abandoned by friends, family, church or other community members ☐ I was not able to take off work, or did not have time to leave my responsibilities ☐ Tests were not available at the lab I was referred to ☐ Other, please specify	

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Q4.4_other	Please specify:	[text entry]	
	Accessing Treatment Services		
Q4.5	How soon after you were notified that your tuberculosis test was positive did you visit the health facility to start treatment for tuberculosis?	1 = Immediately, the same day 2 = Within the same week 3 = After a week, but less than a month 4 = 1-2 months after 5 = More than 2 months after 998 = Don't know 999 = Prefer to not answer	
EN8	"Lastly, let's talk about what happened around the time you started tuberculosis treatment. I will ask about potential challenges you may have experienced in seeking treatment. Please respond 'True' or 'False' if you experienced any of them."		
Q4.7	Before I started tuberculosis treatment, or while being on tuberculosis treatment: <i>Read off the list of options, allowing the respondent to answer if the statement is true or false of their experience.</i>	Mark <u>0</u> for No, and <u>1</u> for Yes Constraint [select multiple] Constraint [Randomize order of response options] ☐ I did not know what to do or where to go to get medications ☐ I did not think the symptoms needed care or treatment ☐ I thought the treatment was expensive ☐ I did not have money for transportation or other costs ☐ The health center was too far ☐ I did not have time to go pick up my medications ☐ I needed permission from family members, friends, religious leaders, or others in the community ☐ I tried to self-medicate/use traditional treatment ☐ I did not trust the health facility/health provider ☐ I thought TB medications were not safe ☐ I did not like the medication side effects ☐ I could not visit the health facility daily to get my medications ☐ I was concerned with lack of privacy/confidentiality ☐ I feared being stigmatized or abandoned by friends, family, church or other community members ☐ I was not able to take off work, or did not have time to leave my responsibilities to go get the medications	

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		☐ I was told medication was not available at the health facility ☐ Other, please specify.	
Q4.7_other	Please specify:	[text entry]	
EN9	“We are now done with the survey.” Thank the respondent for taking the time to complete the survey. Make sure they have a copy of the informed consent document and tell them they may contact the study team for questions. If the respondent provided consent to discuss about his/her TB care with the provider, find the provider and ask the next two questions.		
Q5.1	What type of tuberculosis treatment is the participant taking?	1 = First line treatment 2 = Second line treatment 998 = Don't know/provider not available	Relevance: S16 = [1]
Q5.2	Does the participant have multidrug-resistant tuberculosis?	0 = No 1 = Yes 998 = Don't know/provider not available	Relevance: S16 = [1]