

## Patient-User Survey: GENERIC

**SITE**

Date of interview

Day	Month	Year
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Respondent ID


Clinic or group name

1 <i>Urban</i>	2 <i>Rural</i>	

Condition

Location

Interview Start Time

Urban/Peri-urban/Rural

**“To begin, we would like to ask you some general questions about yourself.”**

### RESPONDENT CHARACTERISTICS

1. Sex

1 F	2 M
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2. Age

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3. Head of household?

1 Yes	0 No
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4. Number in household

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5. Marital status *Tick one only*

1 <i>Never married</i>	2 <i>Married</i>	3 <i>Co-habiting</i>	4 <i>Separated</i>	5 <i>Divorced</i>	6 <i>Widowed</i>
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6. Place of residence: \_\_\_\_\_

(if residence is different from clinic location, probe for reasons)

1 <i>Urban</i>	2 <i>Peri-urban</i>	3 <i>Rural</i>
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7. Employment status *Tick one only*

1 <i>Not working</i>	2 <i>Retired</i>	3 <i>Student</i>	4 <i>Seasonal Work</i>	5 <i>Part-time Work</i>	6 <i>Full-time Work</i>
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8. Occupation *Tick one only*

*Specify*

\_\_\_\_\_

1 <i>Unskilled labour</i>	2 <i>Vocational labour</i>	3 <i>Small business owner or manager</i>	4 <i>Professional</i>
			5 <i>Other</i>

9. Personal income per month

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9.1 “Is this income regular for most months?”

1 Yes	0 No
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10. Household income per month


10.1 “Are you/ or is someone in your household receiving a social grant?”

*Tick one only*

1 Yes <i>Child</i> <i>Disability</i> <i>Older persons</i> <i>Veteran</i>	0 No
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**“What is your highest level of education completed?”** *Tick one only*

1 <i>No Schooling</i>	2 <i>Primary school</i>	3 <i>Secondary school</i>	4 <i>Vocational school</i>	5 <i>University</i>	6 <i>Post-graduate</i>
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11. Religion

1 <i>Protestant</i>	2 <i>Catholic</i>	3 <i>Muslim</i>	4 <i>Hindu</i>	5 <i>None</i>	6 <i>Other (specify):</i>
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### ILLNESS EXPERIENCE and EXPLANATORY MODELS

**“Now, we would like to ask you some general questions about your health.”**

12. **“What symptoms/problems for which you first came to this clinic for help?”** *(Tick all that apply)* **are the**

Narrative: \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

*Tick spontaneous in 12.1 for any that apply*

12.1 **“Have you experienced any of the following symptoms?”** *Tick probe for all that apply*  
*Clarify with respondent to ensure reference to presenting condition, not side effects of treatment*

<b>Patterns of Distress</b> <i>(conditions that it applies to)</i>	<b>Spon</b>	<b>Probe</b>
1 Headaches		
2 Thirst		
3 Regular urination		
4 Bodily pain		
5 Weight change (loss or gain)		
6 Weakness		
7 Poor appetite		

<b>Patterns of Distress</b>	<b>Spon</b>	<b>Probe</b>
8 Nausea & vomiting		
9 Sleep problems		
10 Emotional distress		
11 Skin lesions or discoloration		
12 Chest pains & difficulties breathing		
13 Others (write in):		

12.2 **“Of those symptoms you mentioned, which one is the most troubling for you?”**

*Code single most troubling symptom from above numbered list*

13. **“What name do you give the condition for which you are seeking treatment?”**

*Write name in field and refer to this term in all following questions*

**Narrative** \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

14. **“How long ago were you diagnosed?”**

*Here you can also insert month & year e.g. if client says Jan 2014*

Years	months	days

15. **“People may have various ways of explaining what causes their illness, which may be different from what their doctors or family think.**

**What do you think caused you to have [condition]?”**

Narrative: \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

*Tick ‘Spon’ in grid below for all spontaneously reported Perceived Causes reported*

15.1 **“Have any of the following issues caused [condition]?”**

*Ask respondents about categories not already mentioned spontaneously. Code “probe” for all that apply*

Perceived cause (conditions that it applies to)	Spon	Probe
1 Personal habits - smoking, drinking, drug-taking (HIV, Diabetes, HPT, Depression)		
2 Something in body has gone bad (Diabetes, HPT, Depression)		
3 Something I ate (HIV, Diabetes, HPT, Depression)		
4 Spiritual or magical forces (HIV, Diabetes, HPT, Depression)		

Perceived cause	Spon	Probe
5 Family history (HIV, Diabetes, HPT, Depression)		
6 Other (write in):		
7 Cannot say		

15.2 “Of the causes you mentioned, which one is the most important cause of your [condition]?”

Code single most important Perceived Cause from above numbered list

Narrative: \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

16. “Are there any other health problems that you are currently experiencing?”

List all conditions beside number

1	4
2	5
3	6

16.1 “Are any of the conditions just described related in any way to [state previous condition]?”

3 Yes	2 Possibly	1 Uncertain	0 No
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Tick one only

Narrative: \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

## HELP-SEEKING

“Next, we would like to ask you some general questions about how you have sought help for the condition.”

17. “When you first recognized [condition] as a problem, did you do anything to help yourself at home? If so, what did you do?”

Narrative: \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

Tick ‘spontaneous below for all that apply

17.1 “Did you do any of the following...?”

Probe for categories not previously mentioned. Tick all that apply

Help-Seeking (home)	Spon	Probe
1 Self-treatment with home remedies		
2 Self-treatment with medicines that you already had at home		
3 Changed daily habits		
4 Changed eating habits		

Help-Seeking (home)	Spon	Probe
12 Sought family advice/assistance		
13 Sought friend's advice/assistance		
7 Prayer		
8 Other (specify):		

18. "Many people seek help from various sources, not just doctors. What other kinds of help outside the home have you used?" Tick all spontaneous responses and then probe for categories not mentioned

Help-Seeking (outside)	Spon	Probe
1 Herbalist		
2 Spiritual healer		
3 Community-based health worker		
4 Public primary healthcare facility (e.g. Clinic)		
5 Rural hospital		
6 District level hospital		
7 Private clinic or GP/doctor		

Help-Seeking (outside)	Spon	Probe
8 Nursing home		
9 Church, mosque, temple		
10 Pharmacy		
11 Health support group		
12 Other(specify):		

18.1 "Of those sources of help you mentioned, to which did you go first?"

Code the first source of help sought from above numbered list

Narrative about first source and any subsequent sources mentioned

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19. "How long after your first became aware of the initial symptoms of [condition] did you first seek help from this source?" Refer to the source in question 18

years	months	days	immediately
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19.1 "Did you receive the diagnosis for [condition] from this source?"

Note that diagnostic term might not be the same as from the clinic

1 Yes	0 No
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19.2 If no to 19.1,

"From which source of help you mentioned did you receive your current diagnosis? Or was it this clinic?" Code number from grid in Q18 or code '99' for this clinic

"Now we would like to ask you about seeking help at This Clinic."

20. "How long ago did you start coming to this clinic (or group) for your [condition]?" Refer to the clinic or group from which patient was recruited

years	months	days
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21. How far away do you live from this clinic (group)?

Less than 5km	5-10km
More than 10km	Cannot say

22. "How long does it usually take you to get to this clinic (or group)?" Specify approximate time in hours and minutes, or "cannot say"

Less than 30 min	30min-1 hour
More than 1 hour	Cannot say

23. "How do you travel to this clinic (or group)?"

3 Other	2 Drive	1 Bus/Taxi/Train	0 Walk
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24. "Are there any difficulties getting to this clinic (or group)?"

3 Always	2 Frequently	1 Occasionally	0 Never
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Tick one only

Narrative: \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

25. "Do you have any concerns about the way services are provided at this clinic (or group)? If so, how serious?"

2 Serious concerns	1 Minor concerns	0 No concerns
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Tick one only

Narrative \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

Tick spontaneous below and probe for other issues not mentioned spontaneously, ticking all that apply

25.1 "Have you encountered any of the following problems at this clinic (or group)?"

Concerns about health service	Spon	Probe
1 Long waiting time		
2 Not enough privacy		
3 Doctor or pharmacist is not available		
4 Clinic is not well kempt		

Concerns about health service	Spon	Probe
5 Crowding		
6 Inconvenient hours of opening		
7 Other (specify):		

25.2 "Of the things you mentioned, which one is the biggest concern for you?"  
 (Code from above list)

Narrative \_\_\_\_\_  
 \_\_\_\_\_

## AWARENESS and USE OF MEDICINES

"We would now like to ask you about medicines."

26. "How long have you been taking your treatment?"  
 Note: Client may say I started in 2012 then note the year.

years	months	days

Narrative \_\_\_\_\_  
 \_\_\_\_\_

27. "From which of the following did you first hear about [these medicines]?"

1 This clinic or group
2 Another clinic or group
3 Pharmacist
4 Community health worker
5 Spouse/Family member
6 Friend / colleague
7 Herbalist

8 Spiritual healer
9 TV, radio or Internet
10 Newspaper or magazine
11 Mobile phone message
12 Other (specify):
13 Can't say

Code the first source of information from above numbered list

28. "From which of the following sources, if any, have you received information about using these medicines?"

Tick all that apply

1 Doctor	
2 Clinic Nurse	
3 Community health worker	
4 Pharmacist	
5 Spouse/Family member	
6 Friend / colleague	
7 Herbalist	

8 Spiritual healer	
9 TV, radio or Internet	
10 Newspaper or magazine	
11 Mobile phone message	
12 Other (specify):	

Narrative: \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

28. "Do the medicines usually work well for you?"

3 Don't know	2 Always	1 Sometimes	0 Never
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Tick one only

Narrative \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

29. "How do you feel about the particular features of [the medicines]: Its size, form, and colour?"

Tick one only for each

Like Dislike No opinion Give reasons below:

29.1 Size	2	1	0	
29.2 Form (pill vs. capsule vs. injection)	2	1	0	
29.3 Colour	2	1	0	

Elaborate reasons: \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

30. "Has it been difficult to take your medicines as prescribed? If so, how difficult?"

2 Very Difficult	1 Somewhat difficult	0 Not at all difficult
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Tick one only

Narrative \_\_\_\_\_  
 \_\_\_\_\_

31. "Have you ever had any of the following concerns about your medicines?"

Tick all that apply

Medicine-specific ideas	
1	Not certain about intended effects
2	Harmful side-effects
3	May be fake medicine
4	Not good quality
5	Too many pills to take
6	Body cannot tolerate it

Medicine-specific ideas	
7	Difficult to remember to take it
8	Have to change eating habits
9	Have to change other daily habits
10	Worry about what other people will say who know I am taking this medicine
11	Other (specify):

31.1 "Please explain how you have dealt with these concerns"

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**PREFERENCE FOR TREATMENT**

32. "Have you used your medicines for any other reason apart from treating [condition]?"

3 Yes	2 Possibly	1 Uncertain	0 No
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*Tick one only*

32.1 Write reason(s) here:

33. "Are you aware of any alternative treatments for [condition] apart from the medicines that you are getting?"

3 Yes	2 Possibly	1 Uncertain	0 No
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*Tick one only*

33.1 If yes,

"What are they?" List in grid below beside number

33.2 "Have you used them?" Tick yes or no for all named under Use

Alternative treatment	Use	
	1=Yes	0=No
1		
2		
3		

Alternative treatment	Use	
	1=Yes	0=No
4		
5		
6		

33.3 "Would you prefer any of these over your medicines? If so, which is the most preferred?"

*Enter code number from above or '0' if no preferred alternatives are named*

Narrative: \_\_\_\_\_  
 \_\_\_\_\_

33.4 "What changes have you observed since you started taking treatment for [condition]?"

Narrative: \_\_\_\_\_  
 \_\_\_\_\_

**ACCESS to TREATMENT**

**“Next, we want to know about how you get medicines, including costs and other expenses you might have.”**

**34. “First, from where do you normally obtain your medicines?”**

Narrative: \_\_\_\_\_

\_\_\_\_\_

*Tick normally below for all that apply*

**34.1 “Do you occasionally get your medicines from any of the following sources?”**

*Probe for sources mentioned and tick occasionally for all that apply*

Points of medicine access	Normally	Occasionally
1 This Clinic or Group		
2 Pharmacy		
4 Another clinic		
5 Public hospital e.g. Grootte Schuur		
6 Private clinic/GP		

Points of medicine access	Noramally	Occasionally
7 Support group/Club in the community		
8 Herbalist		
9 Spiritual healer		
10 Family member		
11 Other (specify):		

Narrative: \_\_\_\_\_

**35. “Is it usually difficult to obtain medicines when you need them?” i.e. coming to the clinic for your appointment**

2 Usually difficult	1 Sometimes difficult	0 Never difficult
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*Tick one only*

Narrative: \_\_\_\_\_

**35.1 “Do you occasionally experience the following challenges with regards to collecting your medicines?”**

*Probe for sources mentioned and tick occasionally for all that apply*

Points of medicine access	Normally	Occasionally
1 Too sick to come to the clinic		
2 Forget my appointment		
3 Travel to visit family in another place e.g. E Cape		
4 No transport money to come to the clinic		
5 I feel well and do not need the treatment		
6 My job cannot allow me to come for my appointment		

Points of medicine access	Noramally	Occasionally
6 Too busy with other things		
7 No one to send for collection		
8 I have enough medicines at home and do not need to collect (probe for excess stock)		
9 Weather makes it difficult to come to the clinic		
10 Frequency of appointments too much		
11 Other (specify):		

**35.2 How do you deal with these challenges?**

\_\_\_\_\_



\_\_\_\_\_

\_\_\_\_\_

35.3 “Have you missed an appointment or presented late to collect your medicines in the past 3 months?”

2 Cannot remember	1 No	0 Yes
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35.4 If yes what was/were the reason (s)?

\_\_\_\_\_

\_\_\_\_\_

35.5 What did you do?

\_\_\_\_\_

\_\_\_\_\_

36 “Have you visited the clinic for anything else other than to collect your [condition] medicines in the past 3 months?”

2 Cannot remember	1 No	0 Yes
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36.1 If yes what was/were the reason (s)? *(probe for minor illnesses, pain etc)*

\_\_\_\_\_

\_\_\_\_\_

**FINANCIAL and ECONOMIC FACTORS**

37. “Are there usually additional expenses or costs such as travel, lost income, or food?”

2 Usually	1 Sometimes	0 Never
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*Tick one only*

Narrative \_\_\_\_\_

\_\_\_\_\_

37.1 “Please estimate the total additional expenses per month”

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37.2 “Can you usually afford to pay for them?”

2 Usually	1 Sometimes	0 Never
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*Tick one only*

Narrative: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

37.3 “Have you ever had to give up anything to obtain your treatment?”

3 Yes	2 Possibly	1 Uncertain	0 No
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*Tick one only*

Narrative: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**INFLUENCE OF HEALTHCARE PROVIDER**

*“Before we complete the interview, we have just a few more questions about your caregivers, your family and others.”*

38. “Who are the main persons providing care for you at this clinic or group?”

<i>Tick all that apply</i>	
1 Doctor	
2 Nurse	
3 Counsellors/Community Healthworker	
4 Other (specify):	

39. "Did your caregiver(s) explain your health condition to you in a way that you can understand?"

3 Yes	2 Possibly	1 Uncertain	0 No
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*Tick one only*

Narrative: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

40. "Did your caregiver(s) explain the correct use of the treatment and its effects in a way that you can understand?"

3 Yes	2 Possibly	1 Uncertain	0 No
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*Tick one only*

Narrative: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

41. "Does your caregiver(s) actively encourage you to take your treatment regularly?"

3 Yes	2 Possibly	1 Uncertain	0 No
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*Tick one only*

Narrative: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**INTERPERSONAL SUPPORT and OBSTACLES TO TREATMENT**

42. "Does anyone at home usually help or encourage you to take your treatment regularly?"

2 Usually	1 Sometimes	0 Never
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*Tick one only*

Narrative: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

43. "Is there anyone at home or circumstances that usually make it difficult for you to take your treatment?"

2 Usually	1 Sometimes	0 Never
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*Tick one only*

43.1 "Please describe the circumstances and how you deal with them?"  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

43.2. "Is there anyone else, apart from family members, who usually help or encourage you with your treatment?"

2 Usually	1 Sometimes	0 Never
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*Tick one only*

Narrative: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

43.3 "Have you ever felt the need to hide from family members or others that you are taking treatment?"

3 Yes	2 Possibly	1 Uncertain	0 Never
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*Tick one only*

Narrative: \_\_\_\_\_  
\_\_\_\_\_

44. "Does anyone at home or in the community usually help you treatment if yours run out?"

2 Usually	1 Sometimes	0 Never
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*Tick one only*

Narrative: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**OTHER INFLUENCES ON TREATMENT**

45. "What do you think are the most significant problems for people with [condition] that make it difficult for them to get or take the treatment they need?"

Narrative: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

46. "What suggestions do you have to help other people with [condition] get and take the treatment or important help?"

Narrative: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

***"Thank you very much for your time and willingness to assist with this interview."***

Interview Finish Time

*Interviewer and note-taker should print names and sign and and date below. If only one person conducted interview, fill in information for interview and write 'NA' (not applicable) above note-taker.*

\_\_\_\_\_  
**Interviewer**

\_\_\_\_\_  
**Signature and Date (dd/mm/yyyy)**

\_\_\_\_\_  
**Note-taker**

\_\_\_\_\_  
**Signature and Date (dd/mm/yyyy)**