APPENDIX 1.

Interview guide and responses of a focus group discussion with HIV support group in Nairobi East district

INTRODUCTION

Mouth problems are common in our community and especially among HIV patients. We have invited you to take part in this discussion to assist us to design educational materials that will be used to educate the community in HIV related mouth problems and to seek for care in the health facility. We will ask you to respond to some questions and later to comment on some photographs.

PERCEIVED COMMON MOUTH PROBLEMS/PROBLEMS IN THE OROFACIAL REGION IN THE COMMUNITY

Interviewer: What are mouth problems that face the community?
(Allow at least 7 responses)
(Points to note: Do the participants have to think too hard or is it obvious to them. Record the emotions)

Wounds in the tongue - *'uchawi'* i.e witchraft - people do not believe it is a disease
Allergy to medicines - white lesion '*nyeupe nyeupe' ikikaa sana iningia ndani*
Mdomo unakuwa mwekundu – red mouth
Bleeding/damaged gums (*gums zimen'goka*)
Wounds at the sides of the mouth
Wounds in the throat
Mouth changing black – participant testimony with picture of himself
'Teeth coming out' due to 'damage to the gums'- periodontal disease
Participants with experience of wounds said that the wounds were very painful and prolonged- did not eat for a week
Child of participant- swelling of mouth after healing left black patches.
Tooth cavities

Interviewer: Are these mouth problems common among community members? How often? How do these problems affect the patients? What are the dangers of these problems to the patients? How do they solve these problems?

Mouth problems are common in community and among participants – '*hata sisi tunazo'* – we also have them
Mouth produces bad odour – we cannot socialize
Patients with problem feel stigmatized – They have denial when they have wounds (use herbals)
Affected patient are not able to eat due to pain

Traditional healers (old women) give some leaves to induce diarrhea so that what is in the mouth comes out.
'We do not go to hospital''. People fear to go to hospital because they fear 'VCT' to be tested for HIV- they could be implicated to have HIV
Ignorance - they go for prayer because they think it is witchcraft (*kutupiwa*)
Neglect – they think it will resolve on its own
They fear long queues so they use herbal medicine
Fear community suspicion that they have HIV
The aged are very traditional – believe in herbs

ASSESS POSITIVE AND NEGATIVE ATTITUDE OF THE GROUP TOWARDS ROUTINE ORAL EXAMINATION AT THE HEALTH FACILITY

Interviewer: Would you like your mouth to be examined by the clinician each time you visit the health facility? If the answer is yes probe the participants. What are the disadvantages of routine examination each time you/your community member visits the health facility?
Allow least 7 responses

Do they mention any of the following advantages?: enables the clinician to detect other oral problems, to promote general/oral health of the patient, to detect HIV infection, to give appropriate treatment, early diagnosis and management of the patient, fulfillment to the patients, oral health education .

'We like to be examined every time they come to hospital'
'We think clinician will be able to diagnose you faster, extent of disease, give right medication
'Clinician will see the disease you did not complain of'
'Helpful to us'
'Helps clinician to get right diagnosis'
'We need to educate the community on *kimila'* (harmful traditions)

Interviewer: If the answer is no, probe the participants. What are the disadvantages of routine examination each time you/your community member visits the health facility?
Allow least 7 responses

(Do the participants have any negative attitude towards routine oral examination? Why? Shortage of drugs? Do they feel routine oral examination is unpleasant and acceptable to them/their community? Do they fear repeated drug treatment?)

Please also observe and record their reactions/non verbal responses e.g. frowning, talking in low tones, talking to each other, silence, readiness to respond etc. Listen to what the participants say, paying careful attention to key comments or experiences. Look and listen for preferences in language.

Tunashindwa kununua mswaki, 'we fear to buy a tooth brush because we could buy a wrong one'; 'Wefear to be told that we have a wrong toothbrush '
They fear infecting the clinician.

Believes in the health facility near them.
Naona hakuna ubaya – It is okay if the clinician examined the mouth
Routine examination helps them to get the right medication
They know it is important for the clinician to use the mask but they do not like the clinician to wear a mask due to stigma
The community should be sensitized on the use of masks.

Interviewer: What is your feeling towards a clinician who examines your mouth when you did not have a mouth complaint? *(Probe for any negative cultural and religious beliefs towards oral examination? What are the community fears?)*

'Community does not fear oral examination'. 'The doctor will always explain to you why he is doing oral examination'
'Doctor should explain what he is doing' – general consensus to all the participants
They believe in the experience '*utaalamu*' of the clinician

ASSESS KNOWLEDGE AND EXPERIENCE OF THE PARTICIPANTS REGARDING ORAL HIV LESIONS

Interviewer: Which specific mouth problems are common among HIV patients? *(Allow them to mention at least 5. Do they have to think too hard or is it obvious to them? Do they mention OPC, enlarged parotid gland, herpes simplex/zoster, Kaposi's sarcoma, dry mouth, ulcers, and difficulties in eating and swallowing? If not probe further but do not give a leading question)*

Interviewer: Why is it important to diagnose oral HIV lesions in the community? (*Do they mention that it may be a sign of HIV infection? Probe further about what the participants/ members of the community with oral problems feel about seeking care in the health centre)*
'Community needs education'
'Patients not able to eat or take medication when they have oral problems
'Signs of HIV'; 'We can educate other members of the community'
'One can lose voice'

Interviewer: What does your community believe about mouth problems and in particular oral candidiasis? *(Probe further if the community believes that oral and facial lesions can indicate HIV infection?)*

Interviewer: Why is it important to diagnose oral candidiasis in HIV patients? (*Do they mention that it will enable the clinician will evaluate the response to HAART? If not probe further)*. **Observe their emotions**

Interviewer: Probe further how often they have experienced oral candidiasis in the last one year. Did they seek medical care? Why/why not? (Are they emotional about oral HIV lesions?)
Only three out of the 15 had oral problems in the last one year

They say use of septrin (cotrimoxazole) decreases the incidence of disease – support use of septrin
They all sought care.
They were emotional about oral lesions

ASSESS THE HEALTH SEEKING BEHAVIOUR OF THE PARTICIPANTS REGARDING ORAL HIV LESIONS

Do you/ your community members always report mouth problems to the clinicians? What are the reasons of not reporting mouth problems to the clinician?
The group always report to the clinician
The community members do not easily complain of mouth problem
Fear the clinician might tell them they have bad breath/ dirty mouth and they do not practise oral hygiene
Others feel they should not open mouth to talk to the clinician. 'You only talk of the general problems'
The feel especially women if they have a mouth problems one might also have a problem (wounds) '*huku chini'* in the private parts 'Mouth can speak for other parts of the body*'mdomo unaeleza ile iko ndani*'. Many women with mouth problems also experience problems with candidiasis in their private parts. They may not report to the clinician because they fear vaginal examination.

Reasons for not reporting
Chemist – self medication
Traditional - especially in children they are give herbs
They only come when it is very serious. They do not come because they say '*una tumbo mbaya'* i.e they associate with a stomach problem. *Dawa ya kuhara itatibu* – medicine that induces diarrhea will solve the problem by 'cleaning the gastrointestinal tract'
Aged people say '*una malaria kwa tumbo'* – 'Malaria in the stomach' which can be treated with malaria drugs of herbs
They said 'community should be educated to know it could be an underlying problem'

Do you/they believe the clinician in their health centre is trained to examine the mouth and to give basic oral care for oral HIV lesions?
They unanimously believed the clinician is knowledgeable

Interviewer: What may convince the community to seek oral care seek oral care in the health facility *(Religious leader? Do they listen more to authority or to CHWs?)*

They advocated on door to door community mobilization
They advocated community education
They said, 'many people believe in going to Mombasa (a city in Kenya known for traditional doctors) to seek for traditional medicine'
'Community can be convinced by personal experiences- persuasion'
'CHWs are able to convince the community to seek health care'
'Community education in chiefs' *Barazas*(meetings) but not all people go to *Baraza'.* 'Include a clinician in the *Baraza'*

‘Church - preacher to tell the community about health seeking behaviour –‘*Watu wataamini wachungaji* – ‘community will believe the preacher but some churches discourage their followers from seeking care e.g. *Wakorinos’*
Mganga – maombi – ‘belief in prayers’.
Age difference between patients and socio mobilizers a barrier especially if socio mobilizers are very young’
‘Health education messages need to be repeated’
Some said ‘one to one’ counseling is very effective.
‘During government campaigns, many people accept HIV testing in the door to door strategy where there is ‘one to one’ counseling’
‘Community believes more in HIV infected people who have gone public because they talk from experience’.

Good practices:

- This group does not believe in ‘*dawa ya kiasili’* – traditional medicine. They say ‘*haina kipimo’* i.e there is no defined dosages and one could be overdosed.
- They believe traditional medicine does not work e.g. ‘*madawa ya kuosha’* i.e. medicines that induce diarrhoea do not work.

Dangerous practices in the community:

- *Meno ya plastic*- removal of teeth in infants
- Use of *magad*i (soda ash)in cooking food
- *Kukata kilimi*–– removal of the epiglotis and use of a single knife for all patients *(especially in Maili Saba area)*
- *kisu ni kimoja kinakata kilimi* - One knife is used for all the children hence risk if HIV infection.