Scoping study in preparation for the design of an intervention with mobile young people in Kampala

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Summary

This scoping work explored access to health care services, including HIV care and pre-exposure prophylactics (PrEP) among, young migrant populations particularly those who had stayed in the informal settlements in Kampala for up to one year.

In order to do this, it was important to understand the social structure of where they live, what influences decisions to seek care, including where the health facilities are situated as well as the challenges that impede access.

While we did not find many differences in the barriers and perceptions about health access among the non-migrants, migrants and refugees, those from the Democratic Republic of Congo and migrants from the Karamoja region in Uganda reported receiving a harsh reception and treatment from the health facilities.

We found that general access to care by the migrant population is a challenge due to several factors such as payments asked for at the health facilities, shortage of drugs, unfavourable working hours, language barriers, stigma and marginalization and unfriendly health workers.

As a result, some young people decided not to seek treatment at all, others used remedies such as herbs and substances like khat for illnesses like malaria fever while many sought care after suffering for some time, when the illness did not go away, sometimes after serious damage had been caused.

While health care services are largely provided by government facilities the young people preferred to seek care from small private clinics because the government ones were not stocked with enough medicines, and charged much money more than the private health facilities. There was mention of some institutions that tried to offer young people friendly services and hope. These services provided sexual and reproductive health services and other services such as counselling and translation services. However, some of these institutions decried the fact that they were unable to serve all the young people because of underfunding.

The most common health problems mentioned in the communities were related to the specific environments we found the young people and these included fevers (including malaria), tuberculosis, HIV, skin diseases and poor sanitation.

In terms of specific services, the young people who engaged in sex work were able to access sexual and reproductive health services, although young men pointed out their lack of access to these services. Long-term family planning methods were generally scarce.

While COVID-19 was perceived to be real and a threat, observation of the prevention measures was very low at the time of this study (October 2021) in all the communities, and in some communities COVID 19 was not considered a serious condition. Young

people rarely wore masks. Some people explained that they drank and smeared themselves with alcohol, which they referred to as sanitiser.

With regards to knowledge about PrEP, it was limited, mostly known by those involved in sex work and some young people had difficulty differentiating post exposure prophylactics PEP from PrEP. Nonetheless, a good number of young people said they were willing to use PrEP if it was made available and easily accessible at no charge.

These findings provide some valuable information for in-depth research on barriers to accessing health care in Kampala by mobile populations most especially the migrants and refugees to inform policymakers, planners, and intervention partners who include the leaders of ‘organized groups’ of young people in some communities.

Background

This research work is part of the project `Lending a Hand: developing a support structure for young migrants in South Africa and Uganda' (https://gtr.ukri.org/projects?ref=MR%2FS023607%2F1). Our aim is to develop and test the feasibility of a support structure for young migrants in Uganda and South Africa. We want to support individual migrants' ability to manage and adapt to their place of migration. We are identifying ways in which the key components of the project (positive role models/ "good" social networks, safer environment, health, and social support) may afford protection supporting young migrants to demonstrate resilience with tangible impacts on health (e.g. safer sexual and reproductive health behaviours) and well-being (e.g. hope for the future).

The work which we cover in this report was undertaken in six informal settlements in Kampala to gain a better understanding of who the young migrants are, understand their access to healthcare as well as challenges associated with their access to care. The results will help to identify and inform the preparation of a design for an intervention that would improve the young migrant population's access to health care.

Objective of this scoping study

We sought to understand access to health care services, including pre-exposure prophylactics (PrEP) among young migrant populations, with a particular interest in young migrants who in the last year had moved from a rural setting as well as refugees who have moved to informal settlements in Kampala.

Methodology

Design

The scoping study was conducted in six informal settlements[1] in Kampala known to have large numbers of young migrants due to their close proximity to the city centre. The Good Health for Women Project (GHWP clinic) under MRC/UVRI & LSHTM Uganda Research Unit had undertaken research and service provision in these areas so we wanted to build on this work. The GHWP clinic started in 2008 targeting women aged 15-49 years old at high risk of acquiring HIV and their partners in Kampala and surrounding areas.

Community Entry visits

Two staff members from the GHWP with trusting working relationships with the communities introduced the researcher (Lending a Hand team member) to the stakeholders and other community members.

In each community, introductory meetings were held with influential local stakeholders who consisted of the police officials, community leaders, youth leaders, employers of young people and leaders of 'organized groups' of young people, and health workers.

In order to build collaborative relations within the communities and to ensure the quality of data collected, the researchers took great care in the ways in which the study aim and team were introduced to these communities.

The objectives of the introductory meetings were to: a) introduce the team, explain the background to the study, and the focus of the planned interactions, b) to understand the different stakeholders' roles in the community, and c) gain their trust and support for the discussions in the community.

The stakeholders welcomed the study and provided valuable information on the different aspects of access to health care by young people in their communities and showed enthusiasm that results from the study would provide information to improve people their access to health care services.

During the introductory meetings, local guides were identified who were instrumental in guiding the team around the areas for the discussions. The guides, who were local members of the community, represented the population of interest. They had prior experience of working with GHWP. This existing trust was instrumental in enabling us to be supported by the guides as their co-operation was vital to being able to move freely and safely around the communities, be introduced to young migrants and to map the locations where young people spent their time. With the help of guides, young people were found at their places of work, residences, and at various recreational places such as around pool table venues, bars, sports betting facilities, and health facilities. In each community, several discussions took place and field notes and observations were written at the end of each day.

[1] We have replaced the names of the six places with letters: A, B, C, D, E, F to assist with our anonymisation of these findings.

Data collection

We investigated the experiences of young people's access to health care through informal interactions with the community members and mobile populations including migrants and refugees who willingly agreed to share their perceptions on health care access.

Over the course of a month, we conducted introductory meetings with the community leaders and leaders of 'organized groups' of young people across the six communities to introduce the study to them and solicit their support. Informal interactions were held with the young people (aged 14-24 years old) who included both the migrants and refugees; males and females, we encountered in the community, individually and in groups. The interactions took place during daytime and usually lasted between 5-15 minutes, with the longest being 30 minutes. These discussions were not audio recorded but brief notes were written immediately after the interaction and expanded in detail at the end of the day. Drawing on the research team's extensive experience, this was the most appropriate method to document the discussions and observations.[2]

The interactions were conducted mainly in the local languages (Luganda and Rufumbira). Rufumbira was largely used to interact with recent migrants from Kisoro, and refugees from Congo and Burundi who could not speak Luganda. English was used to interact with the Karamojong and the Acholi in community F. Edward Tumwesige, a Social Scientist, who speaks the two local languages conducted the interactions.

Findings

The structures of young people 'organised groups'

During interactions with stakeholders, we learnt that young people in these settlements lived in what they termed as 'organised groups' and that it was very hard to reach and involve them in interactions. The local leaders explained that these groups live in isolated locations where they form some kind of 'leadership and rules' that govern them and therefore without involving the leaders of these groups, accessing them is very challenging.

Young people in these groups are united by similar economic situations and are involved in similar activities such as collecting empty bottles. This sort of work is commonly referred to as 'kuwenja' (loosely meaning collecting a sack of bottles). They live in very congested makeshift structures made up of wood and polythene bags. The leaders of the groups usually govern how things are done to the extent that even the local community leaders cannot conduct any lawful engagement with them without the knowledge of the group leaders. The local leaders refer to these groupings as 'territories' while police call them 'criminal gangs' but the young people prefer to call their community *'Home of Ghetto boys'*

[2] Rutakumwa, R., J. O. Mugisha, S. Bernays, E. Kabunga, G. Tumwekwase, M. Mbonye and J. Seeley (2020). "Conducting in-depth interviews with and without voice recorders: a comparative analysis." *Qualitative Research* **20**(5): 565-581

For example, when the study team met the local leaders of community A, they explained that it would be very difficult to penetrate the young people's most frequented places. One of the leaders, a female representative said:

> *"if you are new in their areas they are always suspicious of your motives and they can never give you their time. Those are very dangerous areas; they can actually beat you up from there"*

She cautioned the study team saying they risked losing their property if they entered these groups without the presence of their leaders. She linked the study team to 'Big', one of the group leaders who after we explained the study details accepted to move and introduce us to his colleagues throughout the days we interacted with young people in community A. Indeed, when the study team left to go and interact with the young people, they inquired from 'Big' if the team was safe, and he responded:

> *"Nothing will happen to them and their property mama……do not get worried, no one can dare touch your bag when I am walking with you around. When they (other young people) see me walking with some people here they get to know they are our visitors and they are here for something that may benefit them also"*

Inside the ghettos, 'Big' commands respect from his colleagues. They called him all sorts of praise names such as *'presido' (to mean president),* chair (chairman), and kyali (friend/colleague).

Similarly, in community C, the chairman local council linked the study team to a one, 'Black', the leader of a group that lives along the rail track. He also narrated that working with 'Black' was the only way we would be able to freely move around and have fruitful interactions with young people in this area. Fortunately, before the team met 'Black' they met one young man who recognized two members of the study team because he previously accessed care from GHWP.

He led the team to meet 'Black', who thanked the team for respecting the protocol by meeting the local leader first and also recognizing the presence of the leaders of young people in the 'Ghetto'. He narrated that as young people in the Ghetto they also have so many health-related issues and pledged his support to help us reach young people.

> "*You would not have managed, these people here are so sensitive about anything …they are good people if approached rightly. I will be with you when you come back to talk to them and I will support you because you are here for health reasons and even us here we need good health and with that, we cannot fail to support people like you".*

Common health problems

During our interactions with young people, we asked about the health problems they faced and the most commonly reported health problems that were highlighted were malaria and tuberculosis (TB) which were most prevalent among the Karamojong migrants. The young people and local leaders attributed the high rates of TB in their

community to the communal sharing of locally brewed millet known as ‘malwa’. Skin diseases were common among the young men in community C and community E and they attributed this to spending long hours in the trenches cleaning empty bottles before taking them for sale. Sexually transmitted diseases and infections, such as HIV and gonorrhoea, were reported in communities B, C, and D by those engaged in sex work. The conditions reported all appeared connected to the local environmental conditions where they stayed.

> *“People here, including very young girls are suffering from HIV/AIDS. In the evenings, many men come here because there is cheap sex. You can get sex for, as low as 2000 shillings and this is why many of the girls here are sick. They sell (sex) cheaply and get many people (clients) and some infect them with STIs”* Leader of female sex workers in community D.

> *“Many people here suffer from malaria fever. You can see where we live. We live in low land areas with so many mosquitoes and many people here did not get mosquito nets”,* Young migrant, community D.

Other health problems they discussed were due to poor hygiene and sanitation in the absence of safe water resources. These risks were especially acute during rainy periods causing flooding within their residences.

Young people described having to collect and use dirty water from the trenches and attributed this to the high levels of skin diseases and typhoid. In A, young people told us

that the trenches in their community serve multiple purposes as illustrated by a young lady we found chasing young kids who were playing in one of the trenches:

> *"People here use that trench as a urinal, latrine during the night, and women use that water for laundry activities"*

In the absence of good sanitary facilities such as toilets, some resorted to using 'flying' toilets for waste disposal. They described 'flying' toilets as defecating in polythene bags and buckets and then disposing of the waste in the night in the trenches that run between the residences. These remain in the trenches until washed away by the rains. Observations also showed that the majority of households dispose of waste in open garbage tips and trenches, which contributes directly to poor health situations.

Health seeking behaviour

When we went into the community, we first discussed with the young people factors that underlie their health seeking. Firstly, many young people reported that they do not seek health care at all even when they get unwell and this could be due to a number of reasons. For instance, a young man bearing a wide wound on his left foot said he had not yet sought care because he was new in the area and did not know where to access treatment from. He said he had been in Kampala for close to two months.

Similarly, in community C, a group of young migrants said they do not seek healthcare and the most common reasons given were, that they spend much of their time collecting empty plastic bottles down in the slum, they rarely get sick and that they use other options when they get sick (herbs for example).

Indeed, some community members and leaders said that even when health care facilities exist and are in close proximity, several young people do not go there to access healthcare. A garage owner near a Health Centre III employing a good number of young people explained that:

> *'I am always pushing some of those young boys when they fall sick to go there [pointing to the facility], but they do not want to go there. They just want to sit here as the disease progresses. I tell them to at least go and sit at that health centre but they refuse and sit here for the whole day'.*

Asked how they get healed, the middle-aged man who trains and employs so many young people in his motor vehicle garage said he does not know what they use to get healed because after a few days he sees them getting well, holding and carrying machines ready to work again.

Another category of young people said when they fall sick they first try other options such as home treatment using herbs and only go to the health facilities when these options failed to work.

During a discussion in community B, one young man was drinking a concoction of herbs and when asked why he was drinking it, he said he was feeling malaria fever describing

it as the perfect treatment for malaria fever. He said he would only go to the local health facilities, located a few meters away if the illness failed to heal.

The sources of the herbs they used included xxx market (busy market in Kampala) and various herbal shops in town. A few young people said they grow these herbs in pots on their verandas. The most common mentioned herb used was *mululuza* (bitter leaf) to treat malaria fever.

Another category were young people who those said to go immediately to the health facilities once they felt unwell and those are likely to have a history of a chronic illness such as diabetes and high blood pressure and therefore did not want to take chances. Others were those thought to be financially well off and therefore can afford to pay for health care services.

In terms of where they sought the services from, young people mentioned that they sought health care services from both government and private health care facilities. The government facilities included the national referral hospital, those managed by Kampala City Council Authority (KCCA) such a local Health Centre III, and large private owned facilities, and several private clinics and drug shops.[3]

Generally, most of the young people said they accessed health care late when the illness had already taken a toll on their health. Several reasons explained the delay in seeking treatment.

For instance, in community A, young people said they delayed accessing health care because they bought medicines from private health clinics, which they described as 'faster' due to less bureaucracy involved in accessing the care and charge less money compared to the government owned facilities. Some had pride about getting medicines on credit from the private facilities because they regularly go there when ill and have built a good relationship.

> *"The government national referral hospital is there (pointing to the tall buildings) but do you think we go there, we do not go there. You will not get there anything unless you have someone there you know or if you have a lot of money. When I get sick, I go to Aunt xx clinic (a private health clinic run by a nurse), and when I do not have the money she treats me and I pay when I get money"* Male, community A.

[3] The structure of Uganda's health system: Village health teams – made up of volunteers who have basic drugs for uncomplicated treatment. Health centre II – a facility based at the parish level, led by an enrolled nurse or midwife with nursing assistants, serving a few thousand people able to treat common conditions, such as malaria. Health centre III - based at the sub-county level, run by a senior clinical officer with nurses and midwives, and a functioning laboratory, running an outpatient clinic and a maternity ward. Health Centre IV – serves the county, a mini-hospital with inpatient capacity of 50-100 inpatient beds overseen by a medical doctor and nurses/midwives and laboratory staff. Each district should have a hospital which should have the services offered at the Health Centre IV plus specialist clinics.

Other reasons for delaying seeking treatment included the mistreatment young people went through at the hands of the health workers. Some young people said when they got sick they prayed to God to heal them rather than going to the health facilities because of this.

Impeded access to healthcare

Transient lifestyles: 'We won't be here long'

Other reasons that impended young people who had recently moved to the informal settlements from seeking health care access were their transient lifestyles. They described their intentions not to stay in these communities for long. Residing in these informal settlements and the assumption that they would soon 'move on' inhibited their access to health care in Kampala. A group of young people from the Democratic Republic of Congo (DRC) explained how others were reluctant to seek HIV care services in Kampala because they felt they would soon be relocating to other areas, or they would be returning to DRC soon and therefore would access treatment from there. Although they may actually stay for a long time, this expectation that they would be `moving on' meant that many spent long periods of time without accessing critical care. For instance, a male refugee from DRC had this to say:

> *"My sister came to Uganda with HIV but when the medicine she came with got finished she did not go to ask for more from the hospital. She feared they will give her different medicine. She also said she was going to return home soon but she has not gone home, and she is [currently] not on treatment"*

A community health worker in community B explained that young people are frequently relocating from one place to another and that this mobility tends to make their access to healthcare very hard. She narrated she helped young people who tested HIV positive to start antiretroviral therapy (ART) but after a short while, she lost contact with them when they left the community without informing her.

She further described the nature of work of many young people in Kampala that requires them to move all over town in search of work, returning late in the evening or in the night to where they stayed too exhausted to do anything for themselves including taking their medication or even going to the health facility to seek health care.

Because of this mobile lifestyle, even as health workers, when they organize community outreach sessions or a satellite clinic she reported that they hardly find any young people in their communities except for the very ill ones who were unable to move into the centre of town with their colleagues.

Unfavourable times: 'Open at the wrong times and takes too long if I do go'

Although not exclusive to young migrants, the young people we spoke with described how the health facilities' hours of operation do not allow them to access health care because they conflict with their working hours. As noted above, they are working while the clinics are open during the day and once they return to these communities, the services are closed. This meant that some young people delayed seeking healthcare

until their condition was critical and impeded their ability to work. A young commercial sex worker from community F recalled the difficulties they faced accessing health care:

> *"…. we did not have time to go to health facilities because we were in our rooms resting during day time. We only went there when for example, you were very sick and pain did not reduce. When you had not much pain there was no reason to go to the health facility except maybe for family planning"*.

In addition to the unfavourable clinic opening hours, which delayed them attending the clinic. Young people and community leaders reported encountering frustrating and intolerably long waiting times. Despite attending only for critical care, some reported leaving without being attended to as time wasted since it was time spent not earning money. Others reported that they were uncomfortable to be seen there lest they were assumed to be HIV positive, as they needed to wait alongside other patients who were attending to receive their HIV treatment.

> *"You find you have sat there for so many hours and you are mixed with all sorts of other patients including those of HIV. This is so annoying, people who know you can say that you have HIV. If you are not seriously sick you can easily leave the place"*, a young male migrant, F.

> *"Imagine a young man sitting for four hours, do you expect to see him next time? No. They come expecting to get treatment and go and do other things but when they arrive they sit for the whole day and their other activities are affected*", local leader, F.

Young people generally appreciated their need to attend such services, including HIV testing, but reported that existing services were poorly configured to their needs. The community leaders and young people proposed a need for community outreach where some of the minor health services such as HIV testing are conducted within the community to improve the accessibility of such services. Female sex workers in communities F and D proposed establishing clinics that work at night, with tailored services to better meet the needs and risks incurred by commercial sex workers.

Corruption/bribery at government health facilities

Several young people highlighted corruption at the health facilities as one of the major barriers to accessing care in Kampala. It was reported that when they reach the health facilities they are openly asked to pay 'informal fees' or 'give a bribe' to access services that are supposed to be free. Given the considerable waiting times, such payment was expected to be able 'to jump the queue'.

We were told that health facility staff from various departments work in collusion to illegally solicit money from patients. This was not limited to healthcare staff, but bribes were asked for by anyone who holds some sort of authority at the health facility. Although this may have been a barrier everyone was expected to negotiate, the young migrants described being at a particular disadvantage if they were identified as being 'new' to the facility. The

justification was ostensibly to cover guidance for how to navigate the facility to access care. The stakeholders and the community leaders reported that this has a significant adverse impact on the low-income urban dwellers, mostly women and young people with limited access to resources, and discouraged young people, who for the reasons outlined above, were already reluctant to access care.

Besides health facility staff soliciting money from patients, it was reported that there are people who willingly offer money to the health workers to access 'special' and prompt consideration and among people mentioned were the Somali refugees. In community B, many of the Ugandan nationals said that refugees particularly in community B have access to good health care from both private and government facilities because they have the money to pay.

During a discussion with a group of boda boda (motorbike taxi) riders in community B, they narrated that Somalis in community B are given so much attention at a government health facility because they have the money and are fast to heed the health workers' request for a bribe because they have the money.

Besides being rich, during the interactions it was often mentioned that foreigners in Uganda are more serious with their life compared to Ugandans. For example, a group of young men in community B said there are always crowds of Somalis at the health facilities in B and to them, this is because they value their health a lot. The young men in community B said the Somalis have money because they own several businesses and even those who do not own a business are employed in the establishments of Somalis and that this is the reason they sleep in decent housing and own businesses than many nationals.

Some of the leaders and a health worker at a Health Centre IV mentioned that the Somali community in Kampala have got some kind of social security where they periodically pool resources and therefore when a member is sick, they are able to get resources together fast for their member to get access to good health care.

In communities F and A, both located close to the National Referral Hospital, the young people had their reservations about access to healthcare at the hospital. One young female in community F said:

> *"the referral hospital is for the rich. If you are rich you give [a bribe] and get special treatment from there. If you are poor like us, they give you Panadol and send you to the clinics opposite the hospital and these belong to them. We do not waste our time going there"*.

Another female from community A said:

> *"You people you think that at government hospitals medicines are free but that is not the case. Everything is almost paid for. Just go there (referral hospital) and see, what is free is only pain killers"*.

In a discussion in community F, two young men narrated how they carried a friend who had been attacked and beaten by thugs in the night to hospital, but because they did not have money to give health workers at the emergency unit, their friend was left to die on a bed cart in the emergency waiting area. When the body was taken to the mortuary, they did not return to the hospital to collect it and until today they do not know what happened to the body because they did not have the money to pay at the mortuary and neither did they know his relatives.

But not all the health workers in public health facilities ask for a bribe from patients or their carers to access services as illustrated by Irene, a migrant from Burundi.

> *"My young sister joined me here in community F from Burundi while pregnant and she got her antenatal check-ups from hospital. When the time approached to give birth I escorted her and while there our neighbour in the maternity ward asked if we had carried some money with us to give to the health workers to get their maximum attention. My sister and I got scared because we did not enough money with us. But I can tell you that not all Health workers are the same, with my eyes I saw some women being asked for money to buy some items to use during childbirth but there is no money. The woman who helped my sister to deliver asked. She was simply good to us, she was so approachable and friendly".*

Language barriers

Language barriers were reported as affecting migrants' access to care. This was particularly acute for the recent migrants and refugees from the Democratic Republic of Congo living in communities B and C, the Acholi in community F, and the Karamojong in community D all of whom mentioned that they found it difficult to express their health concerns to the health workers. This can inhibit communications between young people and healthcare workers negatively affecting timely diagnoses, comprehension of treatment regimens, and engagement in care. Even when services are operating in the communities in which young migrants live, language barriers can inhibit their engagement in care.

> *"…I have been here for almost a year and in that period health workers have come here once. They were in that building [main hall used for community meetings] but they spoke in Luganda and then I did not know Luganda very well and I just left"*
> Young migrant from Kabale dealing in scrap metal in E.

A refugee from DRC Congo sadly told us that because of the language barrier, when some young people become ill, they just keep home and 'wait for death'.

The impact of this barrier has been recognised by some local health institutions. Individuals working at a local Adolescent Sexual and Reproductive Health, information and service provider, a youth-led organization reported to be teaching migrants and refugees English and Luganda to support communication and some of them have been employed by the centre to help with translations when they receive such clients who cannot express themselves in the local languages.

MUAG has gone further to train young people to provide support to health workers to efficiently communicate to clients with speech impairments.

> *"Here (at the centre) we trained sign language interpreters and translators. We have refugees from Congo, Sudan we trained, and at least these help us communicate with their colleagues. We no longer face so many communication issues with them"*

The ripple effect: complaints of mistreatment by health workers

It was common for young people to talk about how they knew of others who had been poorly treated by healthcare workers. There were concerns about the quality of care, with a number of young reporting that healthcare workers do not conduct a thorough diagnosis of illness one is suffering from and this was reported as one of the reasons for lack of access to health care.

> *"…. sometimes we go there but those people there do not care. They do not do enough to know what the problem is. What you tell them is what they go with to prescribe treatment for you which sometimes does not work"*, Female, community B.

They also reported that health workers mistreated them by being too harsh and arrogant to them. The reputation that healthcare workers had among this group further discouraged them from accessing health services. Many of them described opting for alternative treatments, such as using herbs and sometimes self-medication to avoid relying on the clinics.

The young men in community C pointed towards health workers at a Health Centre IV for humiliating them in front of other patients at the health facility. They expressed their concern over the negative statements made by some health workers who label them; 'smelly, dirty and criminals'. Because they use substances such as khat, marijuana, and other drugs, the visible indicators of substance act as a barrier to access health. One young man shared his experience:

> *"For us here we use our things (substances) and sometimes change the colour of our teeth and when we go to the health facility and they see our teeth they consider us criminals, they shout at us and call us all sorts of names and this is bad"* Eritrean Migrant, F.

During a group interaction with the Karamojong community in community D, narratives of such were common. They said when they visit a health facility, health workers give bad remarks about their traditional dress code and are labelled 'primitive'. The Karamojong women wear a skirt, coloured beads around the neck and a metallic or elastic bands tied around the ankles whereas men wear a piece of cloth over their bodies with plastic bangles. One young man said his brother lost a wife at a health facility in Kampala and her carers blamed health workers for her death because they failed to attend to her when

they were called. He thinks the failure to respond to the carers call was because she was a migrant from the Karamoja region.

In another interaction with the leaders of the Karamojong, such kind of bad remarks were confirmed to be true and are a barrier to health access by young people. The leaders mentioned that marginalization stretches beyond health facilities. For example, the chairperson said the Karamojong in Kampala continue to be excluded from several programs including the Youth Livelihood program because they are looked at as `dirty people' not worth benefiting.

Another elder in the community described the verbal harassment they undergo at the health facilities:

> *"Those people (health workers) need to know that we are also people like them and when we go there, we have gone to receive their services like any other person in Kampala. The way they consider us is not good at all. Many of us here understand Luganda so they backbite us in Luganda that we are Karamojong, we are dirty not knowing that we understand everything they say"*, Resident, D.

Another one showed lack of confidence in the medicines they receive from people who despise them to be the right medication. He thinks they are given less effective or expired medicine because they are considered less human. Asked if they are not healed from the doubtful medicines, he said they get healed by 'God's grace'.

These have devised ways to help them avoid these discriminatory behaviours from health workers. For instance, some Karamojong do not put on their traditional attire but use other clothes so that they are given equal treatment with other patients. Then, those who have lived in Kampala for long term and can speak some Luganda strive to talk to the health workers in Luganda on their arrival to send a message to them that they understand everything they talk to their colleagues about, including if it is against them.

Beyond health, even when the government launches a program such as anti-poverty, the Karamojong narrated how they rarely benefit from such programs. They said the persons tasked with spearheading the program in Kampala rarely come to their community and when they try to follow up on those programs they are blocked along the way; usually made to wait for longer periods, and shouted at, so they end up giving up.

Some young people from DRC recounted similar experiences. They talked about their vulnerabilities in accessing health care in Kampala. One newly arrived young female Congolese said when they go to government health facilities, and they disclose that they are Congolese, health workers tend to evade attending to them and this leaves her wondering why. A fellow Congolese perhaps to answer her said because there are often reports of Ebola outbreaks in Congo, some health workers associate Ebola with Congolese so 'when you say you are a Congolese they see Ebola in you'.

The Congolese migrants and refugees explained that such questions about one's nationality are not asked in private health facilities and this compels those with some

money to access healthcare from private facilities. Those who have lived in Kampala for a while and are quite fluent in Luganda, said they do not want to associate with anything Congolese while seeking care in public health facilities to avoid such prejudice.

It was also noted that Congolese refugees who are in Kampala legally with all the legal documentation have additional support in terms of access to care. For example, these refugees preferred accessing care from institutional health facilities that offer support to refugees such as a United High Commission for Refugees (UNHCR) clinic in community D. It was however noted that such facilities are very limited in Kampala.

Similarly, because of challenges accessing care in Kampala, refugees attached to refugee camps out of Kampala, depending on illness and perceived care, travel to their camps of registration to access treatment and return to Kampala where they are engaged in various economic activities.

> *"It is not easy to get medical care here in Kampala. There are so many challenges especially if you are not a Ugandan. Me sometimes when I get sick because I have all the papers (documentation) I travel to xxx and I get all the treatment from there"*, Female refugee.

Several of the refugees in Kampala earn a living through vending merchandise such as gold jewellery, *Bitenge* (cotton fabric printed in various colours and designs with distinctive borders, used especially for women's clothing), tailoring, and hairdressing in shopping arcades of Kampala.

Another group of young people, who we met as they played 'Ludo', a dice game in a makeshift house in community E, said they had stopped accessing care from government health facilities because they are always made to feel that they are not entitled to the services. If they are treated, care is delivered as though this is a favour rather than a right and so should have no right to complain about how they are treated at the facilities. For many, they reported how their age and their migrant status collided to discredit their legitimacy to access care in the eyes of the healthcare workers. One young man in community C narrated the humiliation he went through at a health facility and attributed it to the fact that he was attended to by older health workers who did not comprehend how young people behave today.

He suggested that health facilities endeavour to recruit health workers who understand and respect all people, are migrant sensitive, and can impartially serve the different types of people in the community. The desire to be treated with dignity was consistently highlighted by young people. The young men and women who previously received care from GHWP said they would have liked to access services from health institutions like the former GHWP clinic. Another young lady in community F and a former client at the GHWP clinic said she did not have the right words to describe the kind of care they received from GHWP. After a few minutes of pausing she said:

"Imagine you are sick, and you are picked up [and taken to the clinic] and [afterwards you are] returned home. The health workers were so friendly to us. I am worried I will not receive the same kind of care from anywhere else. We felt so sad when you closed the clinic".

Other young people who accessed care from this facility described it as a facility with friendly quality services. One female sex worker said she liked the privacy and confidentiality at the health facility which she said is not easily found in many facilities in Kampala.

However, not all experiences with the health workers especially in government health facilities were bad. Richard (not real name) a new migrant from western Uganda said when he visited the referral hospital with an eye problem he was attended to by a female health worker who spoke with him 'nicely' and he praised the extra efforts she put in to see that he went back home with all the prescribed drugs.

Limited drugs

Furthermore, young people and community leaders reported their frustration with a shortage of essential drugs in the health facilities making people fail to seek health care. Participants mentioned that health facilities usually prescribe the medications and are asked to go and buy them from pharmacies outside the health facility or they are asked to return at a later date when the health facility has received new stock.

"In our hospitals what is available are Panadol and then they ask you to buy other medicines from outside. I was even told by people that those pharmacies belong to them and the medicine we are supposed to receive there is sold in their shops", Female leader, F.

Distance and transportation

In some of these communities, leaders and young people reported that the government health facilities are located in distant places away from their communities and this subsequently affects access to healthcare. In community D for example, they noted that the Health Centre IV, the nearest public health facility, is located about 5 kilometres away and as such, the vast majority of the people including young migrants who live in the hard-to-reach areas find it very difficult to travel such a long distance to access healthcare services particularly so because the transportation costs involved are high.

Even where there are available and closer private health institutions, it was reported that the costs of drugs and other medical services in such health facilities are high and many of the young people cannot afford them. Therefore, due to the high costs of transport and drugs, young people find alternative means to treat themselves

"because *of the high boda boda and commuter taxi costs, many people resort to using traditional medicines while others self-medicate through buying drugs in the most prevalent informal drug shops*". Community leader

Whereas health facilities conduct community outreaches as a way of bringing the services closer to the people, it was reported that health workers stop somewhere 'clean' and rarely go deeper into the informal and isolated settlements characterized by narrow and dirty pathways yet this is where several of the young and poorer community members live. One community leader said: *'health workers stage their services meant for the poor communities along the roads and in playgrounds instead of bringing such services down here in the ghetto (slang for untidy settlements)'*.

A similar account of the situation was shared by young people living in the informal settlements of community A as shown in the quote below:

> *"At least [you] have spared some time to come down here, many of the health workers do not because our areas are treated as not reachable. When they come they just park along the road. The problem they do not work with us (leaders) to know how to get to young people"* Youth Leader/guide, A.

It was also reported that health-related information rarely reaches such communities on time since many health workers do not want to come down to the informal settlements to inform and sensitize the community about health.

One young man in the community F said at the peak of COVID-19 he saw many educational materials about COVID-19 in the formal settlements of F and saw several health workers raising awareness about COVID 19 IN the community and few such awareness programs are held in the part of F where he lived.

One of the methods suggested by stakeholders and young people to improve healthcare access by young people was making services available to the informal settlements through working with the community leaders. One community leader in xxx said:

> *"As leaders, we know the geography of our areas, we know the spots where young people live, young people have their leaders and we know their leaders so we can help health workers to map the areas and effectively deliver the services to the target community"*

Availability and access to health care services

The other area of interest during our interactions was around the availability and access to health care services in the community. We explore three services namely sexual and reproductive health services, pre-exposure prophylactics (PrEP) and COVID 19 services at the time of the study.

Sexual and reproductive health

We held interactions with institutions providing sexual and reproductive health services such as an Adolescent Sexual and Reproductive Health Centre. This youth centre provides access to sexual reproductive health information, contraceptive methods, post-abortion care, and STI treatment and prevention to young people in Kampala.

Health workers at this facility reported that they receive so many young people, most especially young girls involved in sex work seeking family planning methods, especially the long term such as intra uterine devices (IUDs) and implants. Health workers however noted that sometimes they are unable to meet their demands because the support from United Nations Population Fund (UNFPA) and other institutions is not sufficient.

For short-term methods such as oral contraceptive pills, injectables and condoms, they said they provide these services sufficiently to the young people who seek them. The centre also works with the Condom Focal Persons, mostly young people to bring condoms closer to where young people live and work to avoid the geographical and social barriers of accessing condoms from the centre.

The centre also provides sexually transmitted disease management and treatment services, but health workers here noted that young people most especially the migrants are hard to serve because of their lifestyle describing them as so mobile, hard to monitor and retain in care. The most common sexually transmitted infections young people present with at the centre are gonorrhoea and syphilis, which was reported to be most prevalent in sex workers.

In community F, the leader of sex workers and other young people reported accessing sexual and health services from a community F Christian organization, an organization under the Roman Catholic church. The leaders of the commercial sex workers collaborate with the organization health workers to extend services closer to groups of sex workers and other marginalized young people in the community F such as the drug users who face difficulties accessing services from the facility.

Whereas sexual and reproductive health services and products provided at these facilities are free of charge, it is not the case in private owned facilities. Therefore, young people who accessed these services had to incur costs yet some of them lacked the money to pay for them. For instance, a 16-year-old girl who is a bar attendant who said that she was introduced to sex work by her old colleagues as a way of boosting her income narrated that

> *She is not allowed to move out of the bar premises but 'stealthily' went to a private health facility to get a family planning method but was asked for money which she did not have. The following day she got a man who she slept with for 10,000 shillings and used the money to access an injectable from a private clinic opposite the bar.*

Apart from the challenge of costs involved in accessing sexual and reproductive health services, we found out that in the Karamojong community, young men and women were not interested in the condoms the team carried along to supply to young people. They told us that their culture does not support condom use because they promote immorality and unfaithfulness. A young Karamojong man said:

"What is that, condoms [are] not for us we do not use condoms. We do not just ask other people here. From childhood, we are told to be faithful to our wives and that is what protects us. We do not use anything"

Previously, Karamojong leaders and elders in Kampala asked young people to abstain from sex until marriage, but on the realization that many contracted HIV and child pregnancies shooting high, the leaders started encouraging and promoting the use of condoms. They however said that it is challenging because of stigmatization associated with picking or buying a condom. Any Karamojong person seen picking or buying a condom is socially regarded as 'spoilt' by the community.

Pre-exposure prophylaxis (PrEP)

In the interactions, we also assessed young people's awareness and access to PrEP. Most young people were not familiar with PrEP. Only a few with a [prior] connection to health institutions and some commercial sex workers had moderate knowledge about PrEP. They described PrEP is a daily pill to stop HIV infection. They had heard about PrEP and related information from KCCA health facilities, the national referral hospital, and HIV research clinics. A few boys in community C and young women in community F reported that they had accessed PrEP information from a nearby research clinic.

A former sex worker who left the trade to engage in other economic activities is one of the community people trained by health institutions to provide PrEP information and access to the sex workers and other members in her community in E. She works with and on behalf of a Health Centre III.

Some young people could not separate PrEP from PEP. For instance, during an interaction with a group of young men at a garage in community C, one young man reported to be using 'tablets' to prevent him from getting HIV but he did not know if it was PrEP or PEP. In community F, an HIV-positive young man and a member of a hospital youth club that sensitises young people in Kampala about HIV and its prevention through music dance and drama (MDD) clearly gave a well-defined distinction between PEP and PrEP.

None of his colleagues during the discussion, including an HIV-positive couple that drank 'malwa', a local millet brew was in the position to share information about PrEP or even PEP. They were however very excited at getting this information.

We explored their willingness to use PrEP and many of them reported high willingness, describing PrEP as a good HIV prevention method they had heard about. For instance, some young girls involved in sex work in F asked for immediate supplies after the discussion about PrEP saying, sometimes their clients force them into unprotected sex and that this would be the perfect prevention method for them in such circumstances.

Despite the presence of some health facilities providing PrEP services in Kampala, it was reported that many of them do not have services tailored to some groups of people. A coordinator of commercial sex workers in communities B and C said there are so many

young sex workers who would wish to start PrEP but are afraid of visiting health facilities to access PrEP. She suggested that health institutions work with the leaders of sex workers to design services that meet such groups of people.

However, there were some concerns about PrEP despite the high willingness. Some young people noted that they were so uncomfortable taking PrEP every day. They narrated how they would prefer a pill they took before any sexual intercourse. A young man in community A said because one is not sick, forgetting to take the pill is very easy. He felt this is so beneficial to sex workers whose risk is higher than others because of their daily sexual engagements.

There were also some misinformation and unsubstantiated rumours regarding PrEP. For instance, a young man narrated that a friend told him that if a person used PrEP for a period of more than a year, the chances of him losing his sexual strength as a man were very high.

The other questions in regard to PrEP included whether one can stop and start PrEP if they can only use PrEP in anticipation of sex or after sex, while others were worried and/or had doubts about efficacy and accessibility issues due to relocation.

COVID-19

Because the study was conducted during times of COVID-19, we also explored young people's awareness about COVID-19 during our interactions. We found out that majority of the young people had heard about COVID-19, and messages about its prevention. The most common prevention messages included hand washing, sanitizing, and wearing faces masks. The sources of these messages included television, radio, banners, and posters pinned in different areas in Kampala as well as from friends and relatives who called them asking them to be so careful.

While many young people acknowledged that COVID 19 existed, some young people were not aware of any cases that existed in their communities and therefore did not see it as a serious health problem to worry about. As a result, they did not find any reason to follow the COVID-19 guidelines like wearing a mask, which they described as 'so inconveniencing'. For example, some young people in community E said COVID-19 existed in other areas in Kampala but not in theirs because there had been no positive case reported in E ever since the first case was reported in Uganda on 21st March 2020.

Indeed, we met a group of adult men in E drinking alcohol and none of them followed the COVID-19 prevention guidelines. They sat so close to each other and exchanged alcohol in small glasses, none of them had a mask on and there was no handwashing facility. When the community guide requested them to maintain social distance and wear their masks, one of the men became harsh saying 'if you think we are sick [of COVID-19] just leave us and go'.

Young people in community C shared similar thoughts. Many young men said that no COVID 19 case had ever been reported in their area at the time of the discussion and

therefore there was no reason to 'burden' themselves observing the COVID-19 guidelines. None of them wore a mask, there was no handwashing facility, no social distancing was observed amongst the young people during the discussion.

Regarding COVID-19 vaccination, young people were aware of the ongoing vaccination program but only a few had received at least one round of the vaccine. The willingness to get vaccinated was observed to be high among young people in some parts of B, upper A and A, and among the community of sex workers in community D. Less willingness was reported in communities B, C, and E near the fuel reserve tanks where several young people doubted the existence of COVID-19 because they had not heard or seen a positive case in their areas.

Among the sex workers, both the teens and young adults involved in sex work were willing or had been vaccinated when the team held interactions with them. They narrated that they had been severely affected by COVID-19 most especially through the strict guidelines put in place that had limited access to their clients. In a discussion with four sex workers who gathered in a small room of their leader in community D, the sex workers said they chose to get vaccinated following the declaration by the President of Uganda that he would fully open the economy when 4.5 million Ugandans are vaccinated.

The commercial sex workers said after this declaration, owners of the places such as hotels and bars where they operate from, working with the leaders of sex workers started sensitizing all sex workers in Kampala to take up COVID-19 vaccination exercise seriously since only vaccinated sex workers would be allowed to operate from their premises.

One of the sex work leaders said because of the financial difficulties sex workers were going through, they welcomed the vaccination call and they took it upon themselves to spread the message to colleagues in Kampala. At the time of the interaction, it was reported that several had received their two jabs and had been issued their vaccination certificates. One of the sex workers said:

> *"I was vaccinated and I have the vaccination card in my room (she went and picked it up in the opposite room). We have been selling sex cheaply to young men here because they do not have money but with this (card) once they open, we will get a lot of money, and life will be nice again"*

However, some sex workers reported that it was depressing that some of their colleagues had tried to get vaccinated in vain. These did not have the identification documents such as the national identity cards and passports that they were being asked to provide at the vaccination centres. The ones affected most were young sex workers below eighteen years of age and those from the neighbouring countries.

The refugees also reported being denied vaccination due to lack of proper documentation. A young migrant from Congo said when the vaccination exercise started he tried to apply

for identification documents but when he was asked for his birth certificate details to confirm he was a Ugandan he stopped making further efforts.

Whereas a few young people had received one or two COVID-19 vaccines at the time of the study and many others were willing to get vaccinated but were being hindered by lack of proper identification documentation, some did not want to associate themselves with the COVID-19 vaccination programs. They were concerned about the (mis)information linking blood clots to vaccination while others said the vaccines were newly discovered and were likely to cause serious side effects in their lives.

Conclusion

The nature of young migrants as highly mobile impedes access to health care services. Planned interventions ought to target their 'organized' structures to ensure that intended services reach them.