NIHR Global Health Research Group on Vaccines for Vulnerable people in Africa (VAnguard).

Activity: Community entry and engagement

Activity site: Koome Subcounty, Mukono District

Activity date: 5th -14th September 2023

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1 Summary

Effective communication and community engagement are crucial elements in community-based research. This report highlights their significance in understanding the influence of structural, social, and biological determinants on vaccine availability and accessibility. We explore various information sources' impact on public perceptions of vaccines and trust, as well as strategies for community entry, support solicitation, and collaboration. This report emphasizes the vital role of robust communication and community engagement in informed decision-making and public health advancement.

The activity was aimed at gaining access into the community and understanding community perceptions, practices and challenges in utilizing available vaccine programs in Koome Islands. Key findings include the influence of misinformation, perceived risk, access challenges due to geographical, structural and cultural factors. Community participation in immunization programs varied by location, with some areas showing high coverage while others faced vaccine hesitancy.

The recommendations emphasized the need for more effective community engagement which is essential to addressing vaccine hesitancy and improving vaccination coverage. These included:

1. Developing tailored communication strategies for different communities.

2. Involving local leaders, VHTs, and cultural/religious leaders to build trust.

3. Expanding healthcare facilities and services, especially in remote areas, to ensure equitable access.

4. The need for continuous health education on vaccines, management of side effects by caregivers and addressing misinformation.

2 Introduction

VAnguard is the NIHR Global Health Research Group on Vaccines for vulnerable people in Africa. It comprises of a multidisciplinary group of vaccine researchers from East Africa and the UK, with expertise ranging from bioscience, social science, and data analysis, to community engagement and research capacity building.

The overall aim of the project is to identify modifiable structural, social, and biological determinants of impaired vaccine impact in vulnerable African communities. This will inform the development of integrated strategies to address them and to promote health equity.

The report delves into the complex interplay of structural and social determinants affecting individual and community health. It examines the critical role of communication and community engagement in understanding the factors that influence vaccine availability and accessibility in Koome Island. It provides insights from fieldwork conducted in September 2023 and outlines findings, challenges, and

recommendations related to vaccine coverage, misinformation, social and structural barriers, and healthcare services.

3 Objective

The objective of this exercise was to introduce the VAnguard project to the community as well as create a platform for community entry in preparation for ethnographic work by Work Package 2; as we seek to answer the second objective of the project: to understand how structural, social, and biological determinants influence vaccine response and impact through various activities. It aimed to explore the relationships between vulnerabilities, health status, and vaccine uptake, moderated by willingness to participate and access.

4 Methodology

This engagement activity utilized a multi-level approach, including meetings with local leaders, health teams, and community members, informal conversations with individuals in the community and health care users (caregivers that had come to seek services at Koome HCIII), observations during the transect walks/ride alongs and review/presentation of vaccine coverage data for the different villages in Koome that informed the selection of the villages. The health workers and local fieldworkers played an active role in facilitating the community discussions.

Four meetings were held with different stakeholders/community gatekeepers, including Sub County, religious, and cultural leaders, as well as health workers. These meetings aimed at introducing the research project, gathering feedback, and obtaining support from local leaders. Discussions covered topics such as common health conditions, vaccine coverage, and suggestions for future research among others. During the meetings, the areas with both high and low vaccine coverage were highlighted as well as the socio-cultural and structural factors affecting vaccine uptake and other health problems affecting the people in this community.

Community members highlighted various factors influencing vaccine uptake, including misinformation, disinformation, long distances to healthcare facilities, and concerns about side effects. The study identified the role of cultural restrictions and structural challenges in shaping vaccination perceptions.

The meetings were held at the Sub County headquarters and in the respective communities, and the team was able to interact with community members at different times and in different spaces, for instance at church, at the shops, new camp and in their immediate neighborhood.

Below is a detailed narrative about the different engagements with stakeholders; observations; and challenges.

4.1 Meetings with stakeholders

4.1.1 Meeting with Subcounty, religious and cultural leaders, and Health Workers

On the 6th of September 2023, a meeting was held with the above-mentioned people. The meeting started at 11.00 am and lasted for 2.5 hours. The meeting was moderated by the Sub County (LCIII) Chairman, Lawrence Kiyingi. The Sub County Chief gave the opening remarks and Flavia presented on the VAnguard project.

The purpose of the meeting was to make a formal presentation to the team about the study, inform them about the objectives and planned procedures, get their feedback on the proposed

plans, get their support in terms of linking the study team with the relevant local leaders, request them to participate in key informant interviews in the later stages of the formative phase and have discussions to get the general/background health information about the catchment areas from the health workers.

•Specific information that was sought included:

i. Common health conditions in the area

ii. Vaccine coverage in the location (which villages/sublocations have more/less uptake, for which vaccines, what are the challenges in delivering vaccines)

iv. Suggestions of sublocations and villages that would be more relevant for the study.

• After the presentation, we had a question-and-answer session as well as opinion sharing. The concerns shared were around:

- Why the VAnguard team is comprised of only women.
- Interaction with the household members in the selected households. For instance, how do we intend to address the dynamics in the households; man/wife; woman and children; multigenerational households. How do we intend to interact with the husband and wife who are engaged in different livelihood activities? For instance, men who are involved in fishing spend a considerable amount of time outside the home.

- Selection of the households; whether the participating families would be randomly selected, or the team would follow given criteria.

Figure 1 Subcounty, religious and cultural leaders, Health Worker, and VAnguard research team

4.1.2 Meeting with Local Council leaders and VHTs

The meeting started at 11.30 am and lasted for 2 hours and was moderated by the Sub County Chairman. Koome main has 15 villages, and all were represented except for Lubembe which has a poor telephone network. Winnie presented on the Vanguard study. The presentation about the study was followed by a presentation from the health facility data officer (as per the table below)

4.1.2.1 Presentation by health workers about vaccine coverage segregated by village/age group.

Routine Immunization for children/Adults		**Outreaches for children/adults**	
Good participation in immunization programs	%	Priority areas	%
Children below 5	< 90	Kitosi – though a mixed community, culture is not a restrictive factor in immunization. Relatively stable community. High reproduction rate has boosted TT vaccination for pregnant mothers	< 90
		Misenyi – Highly mobile due to patterns of fish	< 90
		Kibatiira	Quite high

- Some villages perform better than others, especially those that are closer to the HCIII.
- As a facility they cannot reach all areas, so they identified priority areas.
- They do not have statistics for better performing villages among those who come to the facility, however, Zingoola and Buwe seem to be performing well.
- Kitosi does not have many children coming for routine immunization because of the long distance so the children from this village can only be captured when they organize an outreach in Misenyi.
- Have faced challenges with HPV vaccination so the numbers are still few.
- Lwazi has responded better overtime because of the presence of many schools in the area although there is still a lot of hesitancy among caretakers.
- Regarding COVID 19 vaccination, uptake of booster doses is very low.
- Hepatitis B vaccination has faced many challenges because vaccines for the second round have not been received from the government.
- Busiro has very few people living in the community

Figure 2 Local Council leaders, VHTs and VAnguard Research Team after the meeting

4.1.3 Meeting with selected health facility staff

The team held a meeting with three HWs from Koome Health Centre 3 after the recommendation from the stakeholders' meetings to involve VHTs in the selection of villages.

The villages of Kitosi and Busiro were selected for the community Barazas. And the communities of Myende and Misenyi were selected for the Ride-Along/Transect Walks. However, due to bad weather, the team managed to do Ride Alongs/Transect Walks for Myende and Zingoola.

4.1.4 Community Barazas – Busiro and Kitosi

Busiro – This community was reported to have very low vaccine coverage, and this was attributed to the long distances from the HCIII. Interestingly, this is home to the Sub County Chairperson. Busiro village has four subdivisions Kabembe, Ssama, and Busiro Camp.

The meetings started later than expected because people trickled in slowly into the compound of one of the residents in this area. Most of them had started their day in the garden. They had erected a small tent made of an old canvas sheet and wooden poles. A few benches were provided for the men to sit on while women sat on mats and mainly occupied the right side of the compound. The men dominated the discussion, but the team tried to encourage the women to speak out. The meeting lasted about three hours.

In the absence of the LC 1 Chairperson and VHT member, the Secretary for Defense welcomed the people to the meeting and gave a few remarks. This was followed by a presentation about VAnguard by Flavia. The health Worker (HW), Noordin, also gave a few remarks and the group then had an interactive discussion. After the presentation, we had a question-and-answer session and topics included:

- The criterion to select the 10 households. Discussions around services at the health facilities
- One woman narrated that she had taken her child to the HCIII for vaccination, one week after birth and she was informed that the child had been brought past the recommended vaccination period and therefore the child missed the BCG vaccine. The health worker advised her to take the child to the health facility to receive the BCG vaccine the following week.
- One man made his submission in Runyankore, and a translation was done by one of the VAnguard team members. He was concerned about the lack of drugs and reported that the health workers usually gave them a prescription and they were required to buy drugs from the clinics. 'What should we do?' he asked.
- High transport costs to the health center III and mentioned the ambulance is not affordable.
- Long distance to the health center III. The distance from Busiro to the HCIII is approximately 5 miles, from the first subdivision of the village which is Ssama and 8 miles from the main village of Busiro.
- Drug stock outs: The health worker informed the meeting that the problem of drug stock outs was rampant three years ago and the situation had gradually improved. He urged the people in the community to always take advantage of free testing services and speak up and if need be, confront the HWs if something was not being done right.
- Long waiting hours at the health Centre III; Most of the women mentioned that they wait for long hours at the health facility.
- Few health workers: One man said that Koome has few HWs and so they do not have the capacity to share information with everyone on the Island.

The leaders identified the following common health conditions in the community:

- Mumps (seasonal)
- Snake bites (Experienced almost on a weekly basis)
- Malaria (Acute cases are usually difficult to handle)
- Typhoid (It is not easy to diagnose and treat. Clinics are erroneously diagnosing typhoid. Have no capacity and equipment to do culture and sensitivity tests)
- Gonorrhea (Common among men especially in the camps)
- UTIs (Common and women and men)
- Syphilis and candida
- Dental cavities
- Rotting feet
- Maternal and child health cases
- HCIIIs are not well served by health staff e.g., Surgeons.
- All conditions on the Island are serious because people cannot easily access care.

After the meeting the team had the opportunity for a ride along to see the rest of the community including the camp where most of the people, mainly the temporary residents, reside. The meeting turned out to be an avenue for the community to air out their concerns about the poor services offered at the health center.

Figure 3 Community kimeeza/baraza meeting in Busiro village

Kitosi – The setting for this community is a camp; clustered settlements stretching over a very big area. The population is very mobile, and the dominant activity is fishing (silver fish). A large fleet of boats could be seen in the background and the lawns were covered by big canvas or tarpaulins on which silver fish was being dried. The immunization outreach in this community is every first Friday of the month.

The team went to the community after a heavy downpour and rode for several kilometers. It is one of the furthest villages from the HCIII and apparently one with the highest vaccine coverage (over 95%) and highest attendance at ANC services. The population is very high. The cost of transport is high, it costs about 30,000 Uganda shillings for a single visit to the HCIII.

The meeting was held inside the Pentecostal Church, started at 4.00 pm and lasted for about two and a half hours. The presentation about VAnguard was made by Winnie. After the presentation, we had a question-and-answer session which questions included;

- Inclusion of families that have children that are fully vaccinated in the study.
- Selection of the households without bias.
- Waste disposal and hygiene in the village: During the rainy seasons the camps are always very filthy because of poor waste disposal including human waste. They inquired if we were going to ask about hygiene practices with the intention of training the community on maintaining proper hygiene. There is a lot of poor management of waste especially human waste because most of the people in the community are squatters and there are not able to dig pit latrines.

The community members, when prompted, said that cultural factors have not significantly affected vaccine uptake and that religious leaders have not stopped people from taking up vaccines in this community.

Figure 4 Community kimeeza/baraza meeting in Kitosi village

4.1.4.1 Barriers and facilitators to vaccine uptake

- Misinformation and disinformation; One man referred to the period in the early 2000s in Uganda where after mass vaccination during the Kick Polio out of Uganda campaign, people received information that the wrong drug had been used. He felt that such negative information had continued to affect people's attitudes towards vaccination. His request was that communication about vaccines should be done with some sensitivity. A community member also mentioned that there was low uptake of Hepatitis B because they had heard that the government had used expired vaccines. A woman mentioned that she was told that if a child completes getting the polio vaccine, they can develop Goiter.

- Lack of information on vaccination; Another man (who was very vocal throughout the discussion) also mentioned that vaccination may seem like an old topic but in their community, it is relatively new and if people do not contribute to the discussion about vaccines, it is because of lack of information. He felt that the health workers at the HCIII were militaristic in their approach and there was lack of confidentiality among them.

- Perceptions and experiences on the use vaccines/perceived risk; One older woman mentioned that she had lost her child many years ago due to vaccination and so she wondered if we were talking about a new form of vaccination. A man alleged that his son fell sick after being vaccinated. He says that he thought there was a problem with vaccines in the island and therefore he tried the mainland, and it did not save the situation.

- Low male involvement: Men think that they should just provide for the women, so they are always busy looking for money', said one man. Only one man was identified to be supportive (helps the wife to take the children for vaccination) in the whole village.
- Long distances to the HCIII and the poor terrain affect vaccine uptake.
- Side effects of vaccines and lack of sensitization on how to handle the side effects. Why are caretakers not given health education when they take their children for vaccination, just like during antenatal clinics. Some care takers may not know what to do, say, if they child gets some swelling at the vaccination site (on the thigh or arm). The health worker clarified that the sessions are usually given for mothers who come early to the outreach sites or at the health facility.
- 'Silent law' using the COVID-19 vaccine as an example. The COVID 19 vaccines were taken up by the community because of the 'silent law' by the government. Otherwise, people would not have showed up for vaccination. As a result, the health workers are struggling to get people to take up booster doses. 'The exponential rise in COVID 19 vaccination was matched with an exponential drop'. Similarly, HPV vaccination is challenging because it has something to do with the uterus. 'It is like telling people to remove their uterus by vaccination'. There has generally been limited awareness about the importance of HPV vaccination. He advised that we draw on practical examples of adolescents who were vaccinated, who either derived benefits after vaccination or lost their lives due to lack of vaccination. For other vaccinations like Hepatitis B, the low coverage has been due to laxity on the side of the government/health workers. Many people ended up taking one dose due to failure to supply vaccines to the HCIII. The childhood vaccines have been administered with no major hurdles.
- Migration of fish. During the months of March, April, May, and June there is normally a lot of fish in the water and therefore there is an influx of fish mongers to tap into the resource and therefore increase in the number of people/caretakers seeking vaccination services. However, between the months of August and September, the numbers drop considerably because around this time there is high mobility of fishmongers because they think the fish has migrated to Kenya.

4.1.5 Ride-alongs/transect walks – Zingoola and Myende

We had a transect walk or guided community walk in Zingoola and Myende with the local fieldworker and the local council chairpersons or vice chairpersons of the respective villages. The purpose of the transect walks was to observe the available amenities in the villages for example health facilities, places of worship, proximity to the docking areas within the islands, water sources for domestic use, waste management facilities, health facilities and types of wastes generated. In both villages, the houses are made of wood and clustered settlements. The clustered settlements are referred to as camps, they are characterized by poor human waste management (open defecation) and makeshift toilets and urinals draining directly into the lake. People were seen to be

engaging in multiple activities around the lake area such as cleaning fish, washing clothes (mainly by women), arranging nets and cooking and serving food.

- Myende has a HCII and a private clinic and the distance from Myende to the HCIII in terms of cost is between 20,000-30,000/= for a round trip. It also has a big community radio (mukalakasa).
- Zingoola does not have a health center and therefore they use the HCIII in Bugombe. The distance from Zingoola to the HCIII in terms of cost is approximately 10,000-20,000/= for a round trip.

Figure 5 The VAnguard team during a ride along activity in Busiro

4.1.6 Piloting the interview guide – Lwazi

We conducted two pilot interviews in Lwazi community. We had in-depth interviews with the female care takers because their partners were away fending for the family and informal conversations with children above 8 years.

4.1.7 Observations

The aim of the observations at community level was to understand the day-to-day lives of the communities and factors relevant for vaccine access, uptake and those that can determine vaccine response. We made observations at community level and held informal conversations with community members.

- Social interactions and behaviours in the community-The community members are welcoming. They do not have collective markets and if one wants to buy food, they can only buy it from an individual/household.
- Livelihood activities – the major economic activities are fishing and farming as well as small scale businesses like petty trade and boda boda transport. The crops mainly grown are cassava, sweet potatoes, and yams.
- Livelihood infrastructure and assets-Most of them do not own land and therefore they have makeshift buildings made from wood.
- Community member's interactions with health workers is generally good.

5 Discussion and Recommendations:

- It is important for VAnguard to come up with criteria for selecting the households and bear in mind that Koome is a big community so there should be no limit on the scope to avoid bias.

- A consideration of hard-to-reach areas like Kimi where people face specific vulnerabilities. This was seconded by some of the community leaders. The challenge would be that the budget may not cater for a boat to cross from Koome main to Kimi. They mentioned that there was a boat to facilitate that, however, the project would have to repair the boat and cost share with the community on fuel, to support crossing over. This would be important because according to a presentation made by the health facility data officer in the subsequent meeting highlighted Kimi as one of the areas with low vaccine coverage. Therefore, there was a need to reach out to people in hard-to-reach areas to enable comparisons between households close to and far from the HCIII. However, the discussion about Kimi did not come up in subsequent stakeholder meetings. Koome Island has one HCIII and 2 HCIIs.

- Inclusion of some households that had participated in the previous MRC/URVI studies like POPVAC. This was met with mixed reactions because some of the leaders thought that it might be good to leave out such households. One health worker seemed to have a different view, suggesting that it was important to include one or two families that had participated in POPVAC, particularly those that were hesitant to participate in the study due to misinformation about vaccination programs. He suggested we have 70% of households not involved in the POPVAC and 30% of households that were enrolled in the POPVAC study to capture variations in vaccination experiences.

- The idea of using drama; The idea was appreciated and thought of as one of the ways to capture and sensitize the community about vaccines. However, one Health Worker suggested that the team should leverage on the already existing groups in Koome e.g., SIKYOMU which is a Community based organization that implements the DREAMS program (Determined, Resilient, Empowered AIDS free, Mentored and Safe) which focuses on reducing HIV infection among adolescent girls and young women from the ages of 10 – 24yrs. They use the edutainment format: educating through entertainment. The young girls, who are also the target for HPV, might have a lot to benefit if they participated in the drama. The churches also should be involved in spearheading positive vaccine communication. However, community leaders were not able to work with traditionalists because they did not understand their approaches very well.

- Engaging local leaders and VHTs in research and household selection, as well as considering communities that have strong cultural restrictions for future studies.

The leaders suggested the following stakeholders as potential participants during Key Informant Interviews:

- Local Council leaders
- VHTs
- Religious leaders
    - Adventists
    - Traditional leaders
    - COU
    - Roman Catholic
    - Born Again
    - Muslims
- Parish chiefs
- Health Workers
- LC 3/Sub County Chairman

The traditional leaders were reported to be among the people contributing to vaccine hesitancy in this community and therefore there was need to engage them.

5.1 Action points from Meeting with Subcounty, religious and cultural leaders, and Health Workers

i) Go ahead with data collection (unless there is resistance)
ii) Organize community meetings in the selected villages to introduce the project and share its objectives
iii) Dissemination is important (break down the scientific jargons; use the local language; use examples that people can relate to)
iv) Include information about HPV vaccination (this has received a lot of resistance)
v) Involve religious leaders in demystifying information about vaccines. Take time to explain to religious leaders the importance of childhood vaccines.
vi) Engage local leaders at every stage of the research.

5.2 Action points Meeting with Local Council leaders and VHTs.

i. Selection of villages to be supported by VHTs.
ii. Villages have smaller subdivisions so there should be fairness in selecting households.
iii. Consider conducting meetings in all villages for purposes of future research to create awareness about the project and also to build a foundation for any future studies.
iv. Develop key messages to educate the community about the importance of vaccination, and address common myths, misinformation and disinformation.

5.3 Suggestions for improvement of healthcare services

- The health facility should be upgraded to a HCIV due to the increasing heath needs. They currently do not have a doctor at the facility.
- They should be provided with life jackets for safety while travelling on the lake.

- Immunization outreaches should be intensified for people who live very far from the HCIII.
- Increased budget allocation for health care for people in the Islands
- The health workers together with the local community leaders should create platforms for continuous engagement where community members can speak up about health issues affecting them.
- Establish a health facility near the camp to bring services nearer to the people.
- Improved health education about vaccination for caretakers

5.4 Suggestions for fieldwork

- Involving the VHTs and /or Health Assistants in selecting the households because they interact with the communities on a regular basis and have a closer experience with the families that have been resisting vaccination programs.
- Vaccination coverage in the respective communities to inform the selection of villages.
- Consider communities with strong cultural restrictions.
- Using translators in some villages during the household visits because not everyone understands Luganda.
- There may be need for GPS to support in capturing locations, for example distance from the villages to the different amenities like the health facilities.

5.5 Sources of vaccination information

- Government vaccine schedules are announced on the radios.
- Radio stations like Simba and CBS radio stations
- Routine vaccination and outreaches

5.5.1 Challenges related to fieldwork

Challenges faced in the community included

- Bad terrain especially during the rainy season.
- Long distances between villages and to the health facilities
- The need for improved healthcare services
- The available accommodation facilities were shared with other community members/tenants