ADVOCATES COALITION FOR DEVELOPMENT AND ENVIRONMENT

Barriers to Healthcare-Seeking among Caretakers of Children under five in Uganda

QUALITATIVE EVIDENCE FROM THE DEMAND-SIDE COMPONENT OF THE CODES PROJECT

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List of Acronyms

ACODE	Advocates Coalition for Development and Environment
CFI	Child Fund International
CODES	Community and District Empowerment for Scale-up
DHMT	District Health Management Team
DHO	District Health Officer
FGD	Focus Group Discussion
HSSP III	Health Sector Strategic Plan III (2010/11 – 2014/15)
HUMCs	Health Unit Management Committee
IDI	In-Depth Interview
KII	Key-Informant Interview
LSTM	Liverpool School of Tropical Medicine
RDT	Rapid Diagnostic Test
UNICEF	United Nations Children's Fund
VHTs	Village Health Teams

Executive Summary

Uganda has made commendable achievements in human development and poverty reduction as part of efforts to achieve Millennium Development benchmarks. Despite the efforts, the country's under-five mortality statistics remain high, underscoring the serious challenges that the government faces in its efforts to ensure the survival of children under 5 years of age. The fourth Millennium Development Goal required a two-thirds reduction in child mortality, which implied a decrease in under-five mortality rate from 156 in early 1990s to 56 per 1,000 live births by 2015. By 2015, the child mortality rate had reduced to 90 per 1,000 live births implying a significant stride made in its reduction over the several years. Nevertheless, the rate was still high and the country missed hitting the target of MDG-4 (The Republic of Uganda, 2015; Uganda Bureau of Statistics (UBOS) & ICF International Inc, 2012).

Study Objectives and Methods

This study was designed and done in order to understand the kinds of barriers to care-seeking experienced by low-income caretakers of children under-five years in 16 districts in Uganda. We conducted 80 focus group discussions (FGDs) (five per district), 16 in-depth interviews (one per district) and 32 key-informant interviews (two per district) with health workers—usually the managers of a local health facility (the "in-charge") and a health worker who interacted with children under five. Within each district, three of the FGDs were conducted with female caretakers, one was with male caretakers, and one was a mixed-gender group. Mobilization of participants for FGDs was done with help of district health office in the respective districts.

The data collection guides used in the study covered a number of themes, namely: the availability and accessibility of health units; health facility management and administration; the effects of systemic barriers on care-seeking (especially drug stock-outs and staffing shortages); the ways in which perceived gender roles affect parental and caretaker involvement in child health; and health worker perceptions of care-seeking of under-five health within their districts.

Findings

Study participants registered a number of concerns and complaints when it came to the barriers caretakers experience in trying to seek care for children under five. As expected, distance from health facility was registered as a problem for caretakers living far away from the health facility, though caretakers living

within the five-kilometer catchment area of a facility, which is what the Ministry of Health considers to be an accessible distance, also raised the concern of distance as a challenge. This was attributed to other associated challenges with distance such as the terrain and poor road network. In some districts, the terrain and harsh weather conditions were said to hamper caretakers' access to health facilities that would otherwise be considered "nearby." In addition, the embedded costs associated with transportation made alternative healthcare providers - usually private clinics, drug shops, and herbalists, a cost effective option for many families.

Regarding a gender perspective of household health seeking behavior, we noted that both men and women played significant roles in care-seeking, with women often responsible for the physical care of children and men responsible for the provision of money to cover the costs of transport and prescribed drugs (when necessary). This finding, in particular, lent itself to an argument in favour of including men in all outreach efforts that involve child health. Currently, many such efforts tend to focus primarily on women, who are seen as solely responsible for decision-making about when, where, and how to seek care for children under five.

In terms of health facility management and administration, we inquired about the solicitation of illegal fees from patients, health workers' attitudes and professional conduct, and queue management at the facility. While CODES data from a household study conducted by Child Fund International and the Liverpool School of Tropical Medicine showed incidents of both problems to be relatively low within the two-week period prior to data collection, participants in almost all FGDs that ACODE conducted provided several examples of the impact of illegal-fee solicitation and abusive language used by health workers on health seeking behaviour among caretakers of children under five. Besides, queue management was found to be a challenge in most health facilities where caretakers always queued up for long hours to access the health care they needed for their children. Whereas caretakers of children under five attributed this to late reporting of health workers to duty, and sluggishness among health workers while attending to the patients, health workers attributed it to low staffing levels at health facilities. Moreover, the lack of triaging mechanisms at health facilities to provide a priority to caretakers of children who would be in critical conditions seemed not only to put the lives of the affected children in danger but it also exposed great weaknesses in health facility management and administration.

In general, the demand-side costs of accessing health services appeared to be often compounded by various systemic barriers. These include mainly drug stock-outs, inadequate infrastructure, and understaffing within health facilities. Frequent drug stock-outs within facilities was the most common systemic

barrier reported by the study participants. Drug stock-outs required health workers to send caretakers to private clinics/drug shops to fill prescriptions. Due to frequent stock-outs, some caretakers had given up going to public health facilities altogether. Instead they were going directly to drug shops to purchase whatever medication they believed their children needed. This was done in order to save both time and money that they would otherwise spend on transport.

Policy Priorities

Findings from this study lend themselves to a number of policy priorities that should be considered by policy makers, the Ministry of Health, and technical and political leaders at the district and national level. The most urgent of these issues include the following:

1. **Increase budget allocations for the Ministry of Health:** While there are many gains in efficiency that can and should be made within the health sector (especially in the realm of administration and management), limited budget remains a serious systemic barrier. Until this barrier is properly addressed, improvements in health outcomes will remain largely unattainable.
2. **Ensure that salaries are remitted to health workers on time and in full:** Health workers must be paid on time and in full. Instances in which health workers were going without remuneration for months were reported and this ought to stop. District technical and political leaders need to mobilize whatever political muscle necessary to ensure that agreed upon remuneration is given in a timely manner. If individual districts show little interest in pursuing these issues, civil society organizations and the media may be compelled to step in to play an advocacy role.
3. **Prioritize districts with few health facilities per capita for infrastructural improvements:** Some districts had more health facilities per capita than others. In districts where facility coverage was relatively low, larger proportions of the population were found to rely on a fewer number of facilities. Ensuring that those facilities were well stocked and supported with sound infrastructure came out as extremely important. In addition, instances where a single facility had to cover a wide geographical area to ensure that facility was well outfitted could go far in encouraging caretakers to seek healthcare services in a timely manner, despite some of the hardships associated with transportation and physical access.

4. **Include men in health education outreach efforts related to children under five:** As the findings on gender show, men were often not fully involved in decision-making about care-seeking on behalf of children under five. Because of this, they should be included in all health-related outreach efforts undertaken through health facilities. Often times, women were prioritized in such efforts, primarily because of their outsized role in the physical care provided to children. Given the involvement of many men in financing treatment, and even determining where and when to seek medical care, men cannot be ignored during health-related outreach initiatives designed to sensitize caretakers on ways to improve the health of children under five.

5. **Prioritize quick wins within the district:** Within Uganda's health system, there exist a number of quick wins that district leaders can and should prioritize. Policies to strengthen queue management, for instance, could go far in ensuring that children who come to public health facilities in critical condition are prioritized for care. Similarly, serious commitments to crack down on abusive behaviour and the solicitation of illegal fees ought to be prioritized. However, as with many desirable managerial improvements in service provision, prioritizing such changes is one thing and implementing them is quite another. Although they appear to be *"low-hanging fruit"*— or cheap to implement relative to other supply-side interventions such as ending the challenge of stock-outs on the surface, they pose additional challenges that are linked to incentives such as pay and whether it is adequate and timely, and whether supervisors are facilitated and prevailed upon to carry out their functions.

6. **Publicize efforts at improving service provision:** The Ministry has made a number of investments over the past couple of years to improve the quality of services provided within public health facilities. However, long periods of time in which public facilities have been inadequately staffed have allowed negative perceptions of public provision to take root. Efforts to bring about much-needed change therefore require not simply laying the ground for improving service quality, but public sensitization campaigns that inform end-users about what is being done and, consequently, what they should expect and not expect, let alone accept, when they go to public health facilities in search of care.

1.0 Introduction

1.1 Background

Over the past ten years, Uganda has made considerable strides in trying to reduce the number of children under five years of age who die from preventable or treatable diseases like diarrhea, pneumonia, and malaria, or from diseases that can be prevented through the administration of timely vaccines. Back in 1990, the country's under-five mortality rate was 137 per 1,000 live births but by 2011 the rate had dropped to just 90 deaths per 1,000 live births (Republic of Uganda, 2015). Although still far too high, this reduction suggested real improvement. A myriad of problems continue to plague Uganda's health sector. These range from an inadequate number of public health facilities available to the rural poor, gross underfunding of the sector and ongoing problems with facility management and administration (Colenbrander, Birungi, & Mbonye, 2015; Kajungu, Lukwago, & Tumushabe, 2015).

In spite of these reductions in mortality rates, large numbers of children in Uganda continue to fail to get the healthcare they need. In an effort to understand why this is so, this research report based on use of qualitative research methods highlights the explanations offered by caretakers of children under five. Findings in this report are derived from an operational research that was done at baseline of the 'Community and District Empowerment for Scale-up (CODES) project' in 2014. CODES is an initiative of Uganda's Ministry of Health, UNICEF and the Karolinska Institute in partnership with the Advocates Coalition for Development and Environment (ACODE), Makerere University School of Public Health, Liverpool School of Tropical Medicine, and ChildFund International. CODES is a cluster randomized control trial to determine the ultimately success of an initiative to reduce under-five morbidity and mortality within the project's intervention districts. It is also a multi-year effort to improve public health planning at the district level, while increasing the utilization of services by and for children under five at the community level. The project has main two components- Supply side component and Demand side component. The CODES supply side component is handled by Child Fund International (CFI) and Liverpool School of Tropical Medicine (LSTM). The component is concerned with strengthening the district health systems and health facilities through quality improvement initiatives. On other hand, the demand side component is handled by Advocates Coalition for Development and Environment (ACODE). It is concerned with mobilizing and empowering the communities to demand for and receive better healthcare services. This is done through community dialogues and radio adverts (health messages). Makerere

University School of Public Health and Karolinska Institute jointly handle the project quality assurance, and science /intellectual agenda.

If successful, CODES will help the government to boost its capacity to implement policies and interventions that lead to an array of improvements in health outcomes, especially concerning the control of diarrhea, pneumonia, and malaria; which are three of the top killers of children under five in Uganda today. Findings from the baseline study have continued to inform the subsequent implementation of the CODES project, which runs through 2016.

1.2 Understanding Barriers to Care-Seeking

Uganda's latest Demographic and Health Survey (2011) contains a wealth of household-level data on child health, with sub-sections on vaccine coverage; and prevalence and treatment of diarrhea, pneumonia, and malaria across different regions and demographic groups throughout the country. According to this survey, disparities abound. For instance, a big number of children of children in rural areas reported symptoms of diarrhea, pneumonia, and malaria than in urban areas. A higher prevalence of symptoms was also associated with children from households in the lowest wealth quintile and among children of mothers whose education did not exceed primary school (Uganda Bureau of Statistics (UBOS) & ICF International Inc, August, 2012).

Table 1: Prevalence and Treatment of Symptoms of Diarrhea, Pneumonia, and Malaria in Children under Five (2011)

Diseases	Percentage of children under 5 who had symptoms in the two weeks preceding the survey	Percentage of children with symptoms for whom advice or treatment was sought from a health facility or provider	Percentage of children who received treatment / medication	Percentage of children who took treatment on the same or next day
Diarrhoea	24.1	71.2	53.5	42.5
Acute Respiratory Infection	14.8	78.7	47.4	--
Malaria	40.4	81.6	64.5	--

Source: (Uganda Bureau of Statistics (UBOS) & ICF International Inc, 2012).

While the DHS 2011 contains data on the prevalence and treatment of childhood diseases, it has no survey data on the various challenges experienced by caretakers of children under five when seeking health care for their sick children. The silence of the report on this front is worth noting. According to the findings presented in Table 1, not all children with symptoms of life-threatening diseases are seen by health professionals. This fact begs the question of why this is not happening. In the report, even fewer children with potentially life-threatening symptoms are said to receive treatment or medication, and fewer still take their necessary doses within the prescribed time.

A section on maternal health within the 2011 Uganda Demographic Health Survey notes that almost two-thirds of Ugandan women between the ages of 15-49 reported "serious problems" in accessing health care for themselves, with problems including "getting permission to go for treatment" (5.5%), "getting money for treatment" (48.8%), "distance to health facility" (41.4%), and "not wanting to go alone" (22.4%) (Uganda Bureau of Statistics (UBOS) & ICF International Inc, August, 2012). In all likelihood, many of these challenges also apply to women seeking care on behalf of children under five, although the prevalence of certain challenges may vary. A number of qualitative studies have also documented the kinds of barriers that caretakers of children under five in Uganda experience when attempting to access treatment for children (Golooba-Mutebi F, 2005; Kiwanuka et al., 2008; Mbonye, 2003; Mbonye, Neema, & Magnussen, 2006). However, many of these studies were done over 8 years ago, and may not fully capture the contemporary context of the country's health sector and how it affects care-seeking for children.

Consistent with the above previous studies, ACODE carried out a baseline qualitative study for the CODES project with the goal of understanding better, the array of barriers that caretakers of children under five years of age in 16 districts experience.

Drawing on official DHS data and previous studies on barriers to healthcare seeking on behalf of children under five, the research team at ACODE created key informant and focus group discussion guides and used them to explore the role of health facility management and administration, systemic (supply-side) barriers, distance to the nearest public facilities and gender dynamics within households in care-seeking for children. ACODE also collected data from healthcare providers and administrators of public facilities in the project's 16 districts.

The objectives of the study were:

1. To understand the kinds of barriers to health care-seeking experienced by caretakers of children in the 16 project districts (both intervention and Control districts).

2. To understand the quality of under-five health service provision in the districts
3. To use findings from the survey to develop Citizen Report Cards that would be used as a tool in facilitating community dialogues.

In particular, the interest was in generating answers to the following questions:

1. **Facility Management and Administration:** How do caretakers speak about the behaviour of service providers or the management of health facilities? How are managerial or administrative issues (from the way in which health workers treat patients to wait times) discussed? From the point of view of caretakers, how do such issues effect the care-seeking behaviour?
2. **Systemic Barriers:** What systemic barriers to care are mentioned when caretakers talk about barriers to care (e.g., poor infrastructure within facilities, stock-outs, understaffing)? And how do perceptions of facility-level deficits affect caretaker decision-making when deciding how to treat a child's illness?
3. **Distance:** How do participants who live at varying distances from the nearest public health facility describe barriers to care-seeking differently? In what way, if at all, does distance (3-5 kms vs. 5-7 kms vs. 8-10 kms) affect the utilisation of health facilities?
4. **Gender:** How do different gender groups discuss barriers to care-seeking differently, especially when it comes to the involvement of fathers? What implication does this have for care-seeking?
5. **Health Worker Perceptions:** What differences exist in the way that health workers and caretakers reflect on barriers to care and service quality within health facilities, and what are the potential implications for improving care-seeking?

Answers to each of these questions are presented in subsequent sections of this report. Section 2 outlines the study's design and methodology, while Section 3 presents the study findings. Subsections are devoted to facility management and administration, systemic barriers, distance, gender, and health worker perceptions. Section 4 discusses the relevance of the findings, while Section 5 concludes with policy priorities.

2.0 Study Design and Methodology

2.1 Study Design

The qualitative baseline study was purposive and conducted as operational research in all the Wave One CODES districts (16 districts:- 8 intervention and 8 control districts). The questions that were asked covered a range of themes. These themes included; the most common health problems affecting children in the community; the availability and accessibility of health units; the conduct of health workers; health facility users' perception of quality of healthcare (public versus private facilities) as well as diagnosis and disease recognition (diarrhoea, pneumonia, and malaria). Other questions focused on barriers to the three demand-side determinants of care and health facility user satisfaction (specifically regarding how the quality of health services could be improved in the target communities, and what could make health service planning and implementation better).

2.2 Study Sample and Selection Criteria

The study was conducted in 16 districts divided into intervention and comparison districts. UNICEF (Uganda) categorized these districts prior to the commencement of Wave One phase of the CODES project. District categorization was based on various Uganda's Ministry of Health (National Health Management Information System-two- (NHMIS-2) data on the prevalence of childhood diseases of malaria, pneumonia and diarrhea. CODES project interventions districts include Apac, Arua, Bugiri, Buhweju, Buvuma, Luuka, Maracha, and Masindi, while the comparison districts included Mitooma, Sheema, Alebtong, Iganga, Kamuli, Kasese, Kiryadongo, and Kole. It should also be noted that these study participating districts also represent Uganda's major geographical regions.

Within each district, we conducted five FGDs at varying distances from a mid-level public health facility (usually, but not always, a HC-III) as the central point of reference. To identify the facilities to serve as the focal points for the FGDs, we consulted the District Health Officer (DHO) and other members of the District Health Team (DHT) within each district. Criteria for facility selection included those that were treating high numbers of children that presented with diarrhoea, pneumonia, or malaria, which are among the leading causes of mortality in children under five in Uganda.

Once a facility was identified, our research team then travelled to the unit to meet with its "in-charge," who helped identify three villages whose residents

used the facility by distance stratification. One FGD was held in a village located between the radius of approximately three-to-five kilometers from the reference health facility; two FGDs were conducted in a village between the radius of approximately five to seven kilometers from the facility; and two FGDs were conducted between the radius of approximately eight to ten kilometers from the facility. The purpose of grouping the villages by distance was to tease out whether and how geography and the attending barriers of transportation were somehow linked to the ways in which people discussed the facility and its services.

During the village selection process, the research team worked with health facility in-charges to ensure that even the villages with limited geographical access to private health facilities were selected as well. There were instances in which some villages that were chosen—especially those that were further than 5 km from the reference public health facility—had access to private clinics whose geographical distance was comparable to the nearest public facility. Additionally, the ubiquity of pharmacies / drug shops throughout rural Uganda meant that many of our participants had access to these establishments within a 5 km radius of their homes. That said, access to drug shops was not considered a substitute for access to public facilities.

Through the assistance of Village Health Teams (VHTs) and village-level local leaders (LCs), eight to ten caretakers of children under five were purposively constituted into a focus group discussion. Five focus groups discussions were conducted in each district, three of which comprised exclusively of women, one of which was a mixed gender FGD, and one of which was a male-only group. Each of the three villages identified within each district hosted a female-only FGD. The mixed gender group was held in the medium-distance group (5-7 km from the health facility). The male-only FGD was held in the village located furthest away from the health facility (8-10 km). While women were preferred because of their role in providing physical care to children under five in rural communities in Uganda, the two additional FGDs that included men were constituted to better understand how men spoke about their involvement in caring for children under five.

2.3 Data Collection and Methods

We deployed a total of three (3) data collectors in each district. They had prior experience in qualitative data collection and were deployed to districts where they were fluent in local languages. ACODE-CODES team trained the data collectors for a period of two days. The training encompassed among other things, the goals of the study, the use of focus group discussions and how to facilitate them objectively, and their ethical obligations as data collectors. The

FGD guides used in the study were derived from tools used during an earlier exploratory phase of the CODES project, where methods were being piloted and pretested. We assigned a note-taker and a facilitator for each FGD. On a daily basis, we held debriefing meetings with each team to review progress, make adjustments if necessary, and plan for the next day. Data collection in each district took a total of six days (including travel days).

We used focus group discussions (FGDs) to capture caretaker experiences in accessing health services for children under five in rural Uganda. A total of 80 focus group discussions (FGDs) with caretakers of children under five in 16 districts in Uganda were conducted. The goal of the focus groups discussions was to better understand, as much as possible, the views of caretakers whose interactions with service providers occurred entirely through the care-seeking process. In addition to FGDS, we also conducted key-informant interviews (KIIs) with health workers at the sampled public health facilities in each of the study participating districts, and in-depth interviews (IDIs) with one mother (caretaker) in each district to obtain data about her lived experiences with seeking for healthcare services for her child (ren) suffering from either malaria, pneumonia, and diarrhea.

2.4 Data Management and Analysis

Data collectors tape-recorded and transcribed all the FGDs to text verbatim from the local language in which they were conducted into English. Data collectors further typed all the transcripts into MS Word and ACODE-CODES team reviewed the typed transcripts to ensure that issues and questions of interest were discussed and captured. Transcripts, in which probing within interviews was deemed to have been insufficient, data collectors returned to the field to conduct additional interviews.

We coded and analyzed all transcripts using thematic analysis with a help of a data analysis guide. The guide helped to ensure consistency in thematic coding and analysis. We used Atlas.ti to create query reports of major themes within each district's data set, discussing and conferring with each other periodically to ensure inter-coder reliability and cross-district continuity. Data analysis involved locating and interpreting patterns in focus group responses, with special attention paid to geographical distance and the kinds of efficiency-related barriers (specifically concerning facility management and administration). We also identified commonalities, variations, and disagreements across the interviews with illustrative quotes from participants used to foreground their voices.

2.5 Ethical Considerations

We obtained ethical clearance to conduct this research from the Uganda National Council for Science and Technology (UNCST-SS-2548). Data collectors obtained verbal informed consent from study participants. Data collectors also fully explained the confidentiality safeguards, and participants were informed about probable inconvenience likely to arise because of their participation in the study. They were made aware of the fact that participation was voluntary, confidential, and that they could freely withdraw their participation at any time during the interview or discussion.

3.0 Findings

Caretakers mentioned numerous barriers that inhibit their ability to seek services for children under five, including a lack of drugs at facilities due to regular stock-outs; long waiting times, even for patients in critical condition; a lack of money for transport, especially among patients who lived considerable distances from the 'nearest' facility; inadequate or non-existent roads (which can delay access); unpredictable hours of operation at facilities; health workers who were unprofessional or verbally abusive to patients; general poverty on the part of caretakers; and a lack of knowledge about important health-related issues. While certain illnesses came with their own set of challenges (not having bed nets to protect against malaria, for instance), almost all challenges were mentioned in non-disease-specific contexts.

3.1 Facility Management and Administration

Health facility management and administration issue are multi-dimensional in scope. They are not only critical determinants of quality of healthcare provision but also the nature of health seeking behaviour among caretakers of children under-five in the facility's catchment area. In this study, we focused particularly on three health facility management and administration issues namely, solicitation of illegal fees from patients, health workers' attitudes and professional conduct, and queue management within government health facilities. The study findings show poor management and administration of government health facilities consistent with previous studies in Uganda, including from within the framework of the CODES project (Booth & Cammack, 2013; Bukenya, June, 2013; Golooba-Mutebi F, 2005). From abusive or uncaring behavior to demands for illegal fees, poor queue management; the experience of caretakers over the years has appeared to create resentment and anger towards public health workers—the depth of which may not always be fully reflected in quantitative data on these issues.

3.1.1 Abusive or Uncaring Behaviour among Health Workers

Caretakers across all study districts complained about abusive or unprofessional behaviour among health workers. While some of the stories that caretakers mentioned happened months or even years prior to data collection, numerous incidents were offered as examples of the kinds of stories and experiences that nevertheless appear to linger in the minds of some caretakers, possibly affecting their current attitudes toward government facilities as illustrated by

quotes from two FGDs

> *'. . . at times, we take our children who are in critical conditions and they [health workers] try to show you that they don't care. When they are busy in conversation, they do not want anybody to tell them that look, my child is dying . . . for me, they asked: Do you think that we have never seen children dying? Let it die—the mortuary is open . . . and this happened to me too . . . they asked me . . . do you think that when your child dies, I will not get my salary? . . . or will my salary be reduced because your child has died?. . .'* (FGD Women , Buvuma district).

> *'. . . harsh treatment by health workers prevents some of us from seeking treatment. Those nurses are so rude to us. Sometimes, instead of telling us in a humble way to go and buy drugs from drug shops, they just throw away your book[1] . . .'* (FGD Mixed gender, Alebtong district).

The first quote is an extreme example of the kind of mistreatment and abuse that some caretakers confront at public health facilities. The second quotation highlights a more insidious example of neglect and disregard. Together, both testimonies highlight the kind of mistreatment that some patients expect to receive at public health facilities. As FGD participants from Alebtong note, treatment like this may not only inhibit the timely delivery of quality care, but also prevent some caretakers from seeking services from health facilities.

3.1.2 Solicitation of Illegal Fees

Concerning the solicitation of illegal fees, or bribes, FGD participants described the "invisible" costs involved in securing treatment at ostensibly free facilities. One father in Bugiri recounted this experience at the district hospital, which other FGD participants re-affirmed that it happens.

> *' . . . .In June 2013, I went to Bugiri hospital. I had some money with me but it was less than the 40,000 shillings they [health workers] wanted; it was less by 2,000 shillings. They said that without the 2,000 shillings to make up the amount they wanted, they would not touch my sick child. My child was dying. I went around the hospital and found a man who I asked to give me the 2,000 in exchange for my shoes. He gave me the money but refused to take my shoes. I paid the money and my child got the blood transfusion it needed [the whole FGD nodded in agreement]. Those are the problems we encounter at the health facilities.* (FGD Men, Bugiri district).

[1] In the absence of medical forms, patients are required to buy and maintain an exercise book which documents the patient's medical records and drug prescription history over time.

Asked how they give money to health workers and how they do it, several FGD participants across districts described similar or related processes how such a transaction works out in order to secure timely services from health workers:

> *'. . . we do it privately . . we go to the private room and hand it over when others are not looking. . . then . . . they immediately work on you. You can also signal to him or her. Then, they call you and then you jump the queue . . .the requested money is often like 10,000/= . . . at times, it is even as low as 5,000/= . . . if you go with a coin of 500/= . . well, you may not be attended to* [Laughing]. . .'. (FGD Women, Kasese District).

> *'...You can also signal to him/her that you have put money in the middle of a book...'* (FGD Men, Sheema District).

The quotations highlight the costs that many caretakers face when seeking services at public facilities. While the first one is an example of explicit bribe solicitations from health workers, the second and third highlights the ways in which money changes hands quietly throughout the system. Indeed, even monetary or in-kind "gifts" of gratitude that patients sometimes bestow upon health workers for a job well done can be viewed as contributing to the monetization of a system that should, in fact, be free. For those caretakers who have to factor in transport expenses on top of the payment of illegal fees, the costs of receiving care at public facilities can sometimes end up being prohibitively expensive.

3.1.3 Queue Management

Queue management gauges the extent to which caretakers whose children are in critical condition are triaged by health workers for priority care. A parent in Bugiri described a situation that ended tragically:

> *'. . . I lost a child at Bugiri hospital. I first took him to a private clinic and when the condition worsened, I went to Bugiri hospital. I found very many people in the queue. They sympathized with me and I took the child straight to the health worker. The health worker quarreled and told me to go back and follow the queue. The child died when I was still in the queue. I came back and buried the child.* (FGD Women, Bugiri District)

While the quality of services at Bugiri hospital was described by FGD participants as unusually poor, it should be noted that such scenarios may not be outside the norm when it comes to ineffective triaging within many of the Uganda's public health facilities. Another group of FGD participants in Mitooma had this to say:

> *' . . . the way they relate to us is not good. If you go there with a sick child, they do not ask you how the child started* [showing symptoms]*, how he is feeling . . . And when they do ask you, you see that they are being rude to you. If you reach there with a very sick child, they do not say; ,let us treat this child first, . . . they follow the queue. They do not work on those who are very sick first.* (FGD Women, Mitooma district).

The fact that many caretakers are unsure about the speed of services that they will receive at certain facilities may contribute to decisions on the part of some parents to simply opt out of the public system altogether, sometimes in favor of more risky alternatives, like herbal providers or self-diagnosis at drug shops.

3.2 Systemic Barriers

Uganda's health care system like many other systems experiences deficits that limit its capacity to deliver services to members of the public. Some of the problems are connected to the way in which the system is organized and managed. Systemic barriers are generally those supply-side challenges that the government can by and large address. Below we discuss challenges with commodities, understaffing, and infrastructure.

3.2.1 Drugs and Medical Supplies

In most cases, health workers and caretakers of children under five complained extensively about problems with drug stocks and other medical supplies, noting that government facilities routinely experience shortages and delivery delays due to poor planning and supply-chain management. The consequences of this were found to be potentially dire, especially when perceptions about stock-outs caused caretakers to delay timely care-seeking and the initial utilization of services. As one caretaker in an FGD done in Buvuma put it:

> *Sometimes there are no drugs at public facility. That's why I do not waste my time. I go straight to the bush and collect herbs, cook them, and give to the sick child.* (FGD Women , Buvuma district).

From the perspective of health workers, problems with drug stocks were partially attributable to National Medical Stores' (NMS) "push" system, which gave Health Center IIs and IIIs standard allotments of medicine and essential commodities, regardless of the individual needs of a given catchment area. As one representative health worker put it:

> *There is a problem with the push system that NMS uses. For them, they just push drugs on us; they don't allow us to order . . . ,as a result,*

they give us drugs that are not relevant to the facility. For example, there is one time they brought many drugs for epilepsy, magnesium sulphate, pre-eclampsia drugs, condoms, cannulas, one box of quinine, normal saline. They brought five boxes of medicines that are suitable for plasma expanding during operations, which we don't do. As a result we tend to pile our excess stocks over there and when . . . . hospital staff come here, we tell them to take it. We wish NMS would allow us to order drugs that are relevant to us other than pushing, so it's this system that has failed everything because it just pushes and then we pile there. (KII, Health worker, Bugiri District)

3.2.2 Understaffing within health facilities

Understaffing within public health facilities has been a long-standing problem throughout Uganda. A Ministry of Health publication from 2013 estimated that nationally, facilities were staffed at 50 percent capacity (Republic of Uganda, May 2013). While MOH has been recruiting health workers over the past few years, staffing levels remained far from where they needed to be[2]. Having too few health workers in facilities contributed to long queues, agitated staff (due to overworking), and deficits in proper diagnosis and treatment of patients (especially when high-level medical staff are unavailable) as illustrated by a health worker from Sheema and Bugiri districts:

'. . . the number of health workers we have is not sufficient because at the level of Health Centre III, we should have over eighteen staff, but now we are not even at eight . . . so, that is our problem . . . now, in maternity there is only one staff member . . .in OPD, we have four in total (if everyone is there) and yet they handle more than one hundred clients in a day . . . so that also becomes a problem . . .' (KII, Health worker, Sheema district).

'. . . the other problem is when we go to the main hospital in Bugiri, you find that the health workers really work, but they are very few. You find a health worker who has slept at the hospital and it is just at 10 am that she gets someone to replace her. The patients are also very many and you find that she has worked all night without resting. … If you get there when you find them worn out, you think that they didn't care. If it is a Monday, you might find that there is only one clinical officer. There are many patients and s/he writes without end.

[2] During the 2012/13 financial year, MOH recruited 6,100 new health workers (BMAU 2013).

> *Even the examiner s/he refers you to is not enough because there are many patients. You explain to him/her five diseases and s/he will only write three diseases, so you find that the health workers are few and the patients are very many . . .*'. (FGD Women, Bugiri district).

In spite of the existence of conflicts and disagreements between health workers and caretakers, it is also the case that many patients (as illustrated in the FGD from Bugiri above) are well aware of the constraints under which health workers operate. While some of the problems mentioned on facility management and administration can be tackled with stronger facility-level effort and district oversight, it is also the case that systemic problems like understaffing have very real consequences for the quality of care that health workers are able to offer. Undoubtedly, the MoH is aware of this challenge noted by one in-charge of a public health facility who was aware of the Ministry's effort to push for increased staffing levels:

> "*The MoH recruited all over Uganda . . . in all Health Centre IIIs, they put senior clinical officers . . . the services have improved a lot here*" (KII Health worker, Bugiri district).

3.2.3 Infrastructure

In addition to problems with commodities and human resources, participants also noted the infrastructural problems that plague many public health facilities throughout the country. These ranged from absence of electricity, absence or poor-functioning of refrigerators for vaccines, ill-equipped laboratories and wards, lack of clean piped water, inadequate financing of transportation for health outreach efforts to inadequacy or absence of staff quarters for health workers who need to sleep at the facility. This was compounded by the fact that there are simply too few of public health facilities throughout the country, which creates access-related barriers.

Each of the infrastructural deficits were noted to limit the quality of health service delivery in its own way. The absence of electricity limits the full functioning of labs along with any services that patients may need at night. The absence of staff quarters, meanwhile, limits the number of hours that health workers can work, especially those who live in places where security is not guaranteed. The lack of readily available clean water makes sanitation and hygiene difficult to maintain, hindering almost all aspects of service delivery as illustrated by two different public health facility in-charges:

> '*. . . we do not have housing at the facility . . . so we only work up to a certain time in order to get to our homes early. We can't give people*

> *the best of our services . . . we do not have water at the facility, so we have to hire someone to bring us water from the borehole . . . but each jerry can is 500 (Uganda Shillings) . . . so, imagine how much we spend at the facility on water—and mind you, this is from our own pockets* (KII, Health worker, Luuka District).

> *' the issue of staff accommodation has not been adequately addressed. I don't stay around the health center but ideally as an in-charge, I am supposed to stay at the health center to oversee management. So, staff accommodation has not been adequate, and some of the other staff also sleep away from the station, which makes them arrive late to work. Then there is the issue of the toilet. As you can see, we have only one toilet, which is shared by both the staff and patients. It is also a very big challenge* (KII Health worker, Maracha district)

The kinds of investments needed to fix these problems can only come through an increase in government funding to the health sector. At the most basic level, health workers need to have the resources available to do the work they are entrusted to do. Facilities, meanwhile, need to be hygienic and to have sanitary environments where medical services can be properly provided. Unfortunately, there is no way of side-stepping these requirements. Systemic deficits undergird all other barriers to care presented in this study—even those that can be addressed in marginal ways through improvements in efficiency and management.

3.2.4 Effect of Distance on Healthcare Care-Seeking

In much of rural Uganda, public health facilities—where services are free—are few and far between. While the MoH has deemed any resident who lives within a five-kilometer radius of a health facility to have reasonable access to that facility, it is also true that the differing geography and infrastructure that exists both within and across districts raises questions as to whether the Ministry's assumptions about accessibility hold true everywhere.

While the FGD participants who resided beyond five kilometers of the facility are understood, from the point of view of the MoH, to *not* have reasonable access to the health center in question, we were also interested in the opinions of those participants who *do* reside within five kilometers of the facility, and whether unforeseen barriers affected their care-seeking, as well.

As can be expected, those participants who resided beyond the five-kilometer mark mentioned various factors that inhibited their care-seeking, from poor or impassable roads to the high cost of transport associated with villages that were far from a 'nearby' health facility. Caretakers responded to such

barriers either by delaying treatment at the facility in question (especially in cases in which transportation costs were prohibitively expensive) or by going to other treatment centers, be they private clinics (which required payment for treatment), traditional herbalists, or lower-level facilities that were perhaps less well-equipped with essential drugs or health workers as explained by participants in the following four GFDs:

> *There is no clear road to Apoi HC-III. The road that exists is impassible due to flooding, so you have to go to Ayago HC-II. But this health centre does not function well. There is no medicine and the queues are long because the nurses are few, despite the high numbers of patients. They also don't have beds for admission. The only other alternatives are Akokoro HC-III or Apac hospital. Apoi Health Centre III is not easily accessible, but it is somehow nearer* (FGD Mixed gender 5-7 km from health facility, Apac district).

> *Health facilities are far away from this village, which makes it difficult to seek health services. As a result, we buy medicine from the nearby drug shops. Those who do not have money use traditional medicine like herbs to treat their children* (FGD Women, 8-10 km from health facility, Luuka District).

> *Transportation is difficult in this area. And when you go there [to the government facility], you are told to go to the clinic and buy drugs [because of stock-outs]. So sometimes instead of wasting my time and transport money, I choose to go to the clinic* (FGD Mixed gender, 5-7km from health facility, Buhweju district).

> *In the government health facilities like Kitamiiro, you may not find drugs after walking such a long distance, so some families decide not to go at all. They remain at home and collect herbs* (FGD Women only, 5-7km from health facility, Buvuma district).

Some participants who lived in close proximity to another sub-county or even district said that they would sometimes cross the "border" to access services in the adjacent precinct. However, if the caretakers who engaged in this practice were identified by health workers, their ability to receive services could be put at risk. One in-depth interview respondent from Sheema district who lived between eight and ten kilometers from her sub-county's HC-III said the following:

> *The facility would be accessible, but the terrain is bad which makes transport difficult. There are hills, you climb and slope down, so instead of going to Kakindo [Kyangyenyi HC-III], it is better that you pass here and go to Kyeizooba [in Bushenyi District] because the terrain is good. The only problem is that when we reach there, the nurses ask us many questions about why we cannot use the health*

> *facilities back home, and sometimes they delay attending to us.* (IDI (mother) 8-10km from health facility, Sheema district).

All in all, problems related to distance appear to be affected by the nature of the terrain, vegetation, and road networks in an area. (Places with rough, rocky, steep, or slippery road surfaces can become notoriously impassable during rainy seasons.) According to participants in Luuka, Bugiri, Iganga, Kamuli, and Arua, the existence of swamps, tall savanna grasses, and thick forests also pose difficulties in accessing health facilities in the area.

> *The roads are bad, sometimes impassable during the rainy season. In fact, there are generally no roads in this area. You know, Namasagali is full of swamps like you have seen. Most people have to walk on foot to reach the facility, but mothers fear to walk through the swamps.* (KII, Health worker, Kamuli district).

> *We walk on foot to reach the company (Rhino Camp HC-IV). The animals always scare us along the way because it is sometimes hard to see them coming in the tall grass—especially when you use the short-cut because the place is very far. If the child is badly off we use* boda-bodas *and pay up to UGX 15,000, which is very expensive for the majority of us.* (FGD Women, 8-10km from health facility, Arua district).

One striking finding was that some participants who lived within three to five kilometers of the nearest public health center also complained about distance-related barriers to care-seeking—especially participants who, because of transportation costs, were relegated to walking with sick children to the facility:

> *The problem we have is that we don't have a nearby health facility. When a child is very sick, sometimes it is impossible to reach places like Kabwohe and* boda bodas *charge a lot of money, which we don't have. Because of this, the children end up dying before reaching the health facility. The private clinics that are nearby charge high prices. When you take a child there, they ask for UGX 10,000 and a common person like me doesn't have that money. That is my problem.* (FGD women, 3-5 km from health facility, Sheema District).

> *The distance to Bihanga HC-III is far and the road is very bad because of the hills. We usually walk on foot but sometimes we use* boda bodas*, which cost UGX 2,000. But if it is at night, then they can charge you any amount of money they want.* (FGD women only, 3-5 km from health facility, Buhweju district).

Again, the geographical and infrastructural barriers of a given area can render even "nearby" facilities inaccessible, especially in remote areas or during inclement weather. The apparent result of all this is that many parents and

caretakers make sub-optimal choices: either waiting and hoping that a child's ailment goes away on its own without treatment, or choosing to self-medicate (either through private drug shops or with herbs). The effect of distance barriers and the hidden costs of transport can even lead to drug sharing and the distribution of partial doses to children.

> *The clinics do not give us enough medicine because they are expensive [or perhaps there are stock-outs], and yet the health centre is very far. So if you go there one day and get medicine for one child, you share it with the rest of the sick children because you cannot carry all the five children to the health centre because of the long distance. Even the nurse will abuse you.* (FGD women, 8-10km from health facility, Apac district).

3.3 Gender Norms

When it came to care-seeking on behalf of sick children participants (both male and female) described a general pattern of behavior and expectations assigned to the different genders. When it comes to financing a child's treatment—which could mean anything from covering the cost of transportation to paying for medicine from a drug shop or clinic—participants across districts noted that men are expected to foot the bills. This could be due to gender norms, or because men are frequently the principal wage earners, or some combination of both factors (which influence each other). As keepers of the family purse, men appeared to have quite a bit of decision-making authority about care-seeking on behalf of sick children—which included authority over how to mobilize resources to cover medical treatment when cash was not readily available (from the selling of household goods to the borrowing of cash from family members or neighbors). When asked, for instance, "who decides when and where to take children when they fall sick?" FGD participants in Bugiri and Alebtong said the following:

> *'. . . we decide because we are the one who provide the money. Even if the woman decides, if she does not have any money, she cannot do much. we have to plan and see how we can get the money. So, If we have the money, we decide where the child has to be taken—for example, to Matiki Health Facility or Kavule . . .'* (FGD men, Bugiri district).

> *'. . . it's a man [who is responsible for paying]. It's because he has the money and therefore, he has the responsibility. If he tells you to take the child to a particular health facility and you don't, he will leave you to face it all on your own . . .'* (FGD Women, Bugiri district).

> *When there is no money for transport, my husband borrows money from a friend. But last time he sold our remaining cock to raise money.* (FGD Mixed-gender Alebtong district).

That said, participants also noted that women, as principal caretakers of children under five, were often times the ones to first identify the onset of a given illness, and to alert the child's other caretaker(s) of the problems at hand. Additionally, women were often the ones responsible for seeking care for sick children. In certain households, at least, when money was not forthcoming from men, some women choose to exercise their own prerogatives—to the extent possible, given their financial constraints—about where and when to seek treatment. Three different FGDs put it this way:

> *'. . . most fathers are so reluctant when it comes to childhood illnesses. With me, I do not waste time. I just put my child on my back and head to the health facility. It's upon him to follow us or not . . .'* (FGD Mixed-gender, Alebtong district,)

> *'. . . with some husbands, when asked for money for medication, their response is 'we don't have money.' So this forces us to go and borrow money from our relatives or friends, or use herbs . . . '* (FGD Mixed-gender, Iganga District).

> *'. . . If he is not around, you have to walk and go to the health centre yourself. You cannot sit back and watch your child die while waiting for the man to come back . . .'* (FGD Women , Bugiri District).

It was noted that when husbands were available, active, and capable of mobilizing resources, women caretakers had the option to choose to (and were expected to) refer to the men in their lives. When men are absent, however, women were expected to shoulder the entire caretaking burden themselves. A woman stated:

> *'. . . mine simply says, 'take the child to the health facility.' He is difficult. He sends you to the health facility but he does not care. He sends you to the health facility but does not facilitate you with any money . . .'* (FGD women FGD, Bugiri district).

> *'. . . since I've been here, I have never seen men bring their children to this health facility. I always see mothers bring their children. So the health seeking behaviour of the men towards their children, I really cannot understand it. I can't judge them; maybe because I am new, but I haven't seen any men bring their children to this facility. So this probably shows me that men are not up to it. You know traditionally, in our community here, people think the issues*

> *of feeding, taking children to the hospital, knowing their health, it's a woman's thing and it's not for the men . . .'* (KII, Health worker, Maracha district).

These critiques of male involvement aside, it was also the case that some men in the FGDs were adamant about their involvement in their children's healthcare, beyond the mere financing of treatment:

> *'. . . if the woman is not around, I have the responsibility to give the child medicine. There was time when our child had malaria and I had to give him tablets and syrups. Some women are too lazy to give children drugs on time* (A man's voice in mixed-gender FGD, Bugiri district). A man said:
>
> *'. . . when my child dies, it is my loss, so I have to take him to the hospital. It is my responsibility as a man to take my child to a health facility . . .'* (FGD Men, Kasese District).

What these findings suggest is that despite general trends in behavior that can be characterized in gendered ways, there exists a degree of flexibility within many households when it comes to the roles that people assume in care-seeking for children—flexibility that appears to be contingent upon finances, the availability of parents at the onset of an illness, and perhaps even perceptions about the severity of the illness at hand.

3.4 Health Worker Perceptions on Barriers to Care-seeking

According to health workers, systemic barriers not only affect care-seeking among users, but also impede service provision among providers. Such barriers include inadequate and delayed salaries, regular drug stock-outs, inadequate equipment and material supplies, understaffing, insufficient electricity, inadequate (or nonexistent) staff accommodations, and inadequate space or infrastructure within the facility for serving patients.

> *We have many challenges but let me mention the following: our laboratory is not efficient because there are no laboratory reagents, and when we refer the children to other health facilities their parents don't go there; instead they go back home to pursue other treatment. We also have regular stock-outs of drugs and supplies. And we lack a community follow-up mechanism because none of the staff at the health center has a motorcycle. This is the work of the government.* (KII, Health worker, Kasese district).
>
> *The health service delivery here is not easy. Sometimes you cannot perform when the patients come in large numbers and you feel all of them need to be served. Ideally you are supposed to interact*

> *with the patients at least 15 minutes, meaning that if you take the government working hours, I don't think it is more than 45 patients [per day], and you find the patients come in a large numbers, more than 100 or even 200 in a day.* (KII, Health Worker, Maracha district).

Interestingly, some health workers concurred with caretakers about weaknesses in health facility management and administration. Among other things, the views of health workers helped illuminate the difficult contexts in which they worked, as one in-charge in Luuka noted:

> *Our pay is not good enough. Our salary is a bit small and does not come on time. We have to wait a long time, and sometimes you even forget that you earn a salary, which is why we have to dig and do other work besides being at the facility. And when we are paid, they pay for only previous months, and then it becomes a cycle.* (KII, Health worker, Luuka district)

This kind of context is extremely important, given patient complaints about absenteeism and tardiness. When discussing issues of allegations related to abusive or unprofessional conduct toward patients, health workers had this to say:

> *Some patients say that the way in which some health workers communicate is not ideal, that some health workers use "high tones." But this is because some mothers come to the health facility after having wasted time at drug sellers or using traditional herbs, which annoys health workers. For example, this past Monday, there was a mother who came in with anemic baby from Ndotwe and the health worker was harsh to her.* (KII Health worker, Buvuma district)

> *We have had cases of communities complaining about rudeness and negligence on the part of health workers. On that issue, I have to be sincere. Some of us health workers are not friendly in the way that we talk and react to patients, so we have heard these cases and even we know that getting a smile from such a health worker is not easy. I always tell our health workers that smiling at a patient is as good as giving something to a patient to begin with. Once in a while the community complains about our interpersonal relations, which are not the best.* (KII, Health worker, Kamuli district).

Notwithstanding the existing systemic factors that affect service delivery, health workers also perceived poor care-seeking behaviour among the people in their catchment areas. They worried that that caretakers fail to fully and properly utilize the services available at the health facilities in their area, in part due to inadequate information, in part because of entrenched systemic barriers (including those exacerbated by distance), and in part because of caretaker

confidence in the efficacy of traditional medicine. As a result of all this, districts struggle with poor immunization rates, potentially life-threatening delays in seeking health care for sick children, and drug abuse or non-adherence, among other things.

> *Caretakers just go to traditional healers for "millet extraction" whereby they cut and remove some fat from their body, thinking that the illness is* 'oburo' *when it is not. And for diarrhea, they rush there thinking that it is* ebiino *[milk teeth], so they just go for false teeth extraction whereby they get these canines from both sides removed, thinking that they are causing diarrhea, when they are not.... And for malaria, people have now started to think that it is sorcery—*'amahembe'*—not knowing that it is malaria.* (KII, health worker, Sheema district).

> *They first go to the drug shops or private clinics, and sometimes they start treatment with herbs. Many of them bring their children covered with herbs. We experience many parents bringing us children who are very sick following their failure to cure them with herbs or drugs bought from private clinics and drug shops.* (KII, Health worker, Iganga district)

> *Pneumonia has been challenging because sometimes mothers take their time, they delay bringing the sick children here, and when the condition worsens they come here for treatment. At times you may want to admit this child and put it on IV treatment, but you lack that intravenous supplies for the baby. There you have no alternative other than referral. This means you are unable to treat that child fully, while knowing that you could have if the right equipment was available or maybe if the child had been brought early enough.* (KII, Health worker, Apac District).

Needless to say, the constant flow of such cases—of caretakers not adhering to proper protocol (for whatever reason), coupled with a lack of equipment and resources needed to treat children who are seriously ill—can take their toll on the ability of health workers to maintain the professional, caring demeanor needed to treat patients and secure their trust. The combination of poor facility management, systemic barriers to care-seeking, and a lack of health education on the part of caretakers appears to have created a combustible scenario that increasingly strains the already fragile relationships that exist between health workers and the public they are meant to heal.

4.0 Conclusions

From the above findings, it can be deduced that barriers to healthcare seeking among caretakers of children under-five in Uganda are interrelated in multiple and complex ways according to the context in which they occur. Health seeking behaviour among caretakers of children under-five is largely shaped by socio-economic status and gender relations in homes, health facility management and administration as well as the exiting systemic issues in the provision of health services.

The household's socio-economic status coupled with gender norms determines caretakers' responsiveness to child's illnesses in terms of timeliness in seeking healthcare. This combination determines when, where and who to seek health services. In the rural setting in most of the study participating districts within patriarchal arrangements, men are regarded as 'bread winners' for their families and this makes them pre-occupied with the responsibilities of looking for money to make ends meet. Consequently, their spouses take-up larger responsibilities of healthcare seeking for the sick children, as long as men manage to provide some money that might be needed for transportation to the health facility. Thus, women can decide when and where to seek health services from.

Distance and associated costs to access a health facility appears to mediate through this combination. Long distance and associated transportation costs to access a public health facility seems to be such a major interlocking factor in the caretakers' health seeking behaviour and a major barrier to seeking health care across study participants in various distance cohorts of study participating districts. Moreover, including those participants who live within the Ministry of Health recommended 5 km radius from a public health facility. With long distances and associated costs to reach public health facilities, most caretakers tend to resort to alternative choices of healthcare including easily accessible traditional healers and use of herbs in treating childhood diseases. Self-medication also becomes inevitable which manifests itself through buying incomplete doses (since most caretakers often cannot afford to buy complete doses) from private clinics / drug shops which are within their proximity, and sharing doses among multiple sick children. Most caretakers especially those from beyond 5 km radius from health facility tend to choose seeking health services for children from hardly accessible public health facilities only for those illnesses that warrant going there - cases of critical condition. Generally, despite encumbrances associated with long distances, caretakers seem to be trusting public health facilities to handle childhood illnesses. At least amidst other alternative choices, a public health facility is always looked at by caretakers as either the first or last choice depending on the many circumstances surrounding seeking healthcare.

They are only disappointed by other interlocking factors such as health facility management and administration issues and other systemic issues.

Health facility management and administration issues notably the courteousness with which health workers 'treat' (attend to) patients, and the working relations between health workers and health service users also greatly affect care-seeking among the caretakers. Issues to do with health workers soliciting illegal fees from the poor caretakers who perhaps could have used the little they had to meet high costs of transportation to reach the health facility, poor queue management and absence of triaging mechanisms which makes caretakers including those with children in critical conditions, spend long waiting hours to access the health service they need at a health facility, and health workers' use of unprofessional / insulting language on caretakers, all largely affect caretakers seeking behaviour. It is observed that when these issues are not adequately addressed by health facility in-charges, health facility management committees (HUMCs), sub-county and district leadership, even when the larger systemic issues seem to improve, health service provision may not correspondingly improve at the service point- health facility.

Lastly but not least, systemic issues which are largely a preserve of the central government (Ministry of Health) are great barriers to health care-seeking among caretakers of under-five children in multiple ways. The frequent drug stock-outs in public health facilities, understaffing, poor and untimely payment for health workers, and inadequate facility infrastructure (working space, staff accommodation, equipment, and amenities) appear to be greatly jeopardizing not only service delivery at the service point (health facility) but also service utilization by caretakers of children under five by compelling them to use alternative choices of care and other risky health seeking behaviour as earlier mentioned above. Compared to health facility management and administration issues appear to be a "low-hanging fruit"- can be addressed with minimal resources, addressing systemic issues require substantial amount of resources from the central government. This implies that appropriate national-level health sector planning and budgeting is crucial.

5.0 Policy Recommendations

The findings from this study lend themselves to a number of priorities that should be considered by policy makers, the Ministry of Health, and technical and political leaders at the district and national level. The most urgent of these issues are put forward below:

1. **Increase Budget Allocations for the Ministry of Health:** While there are many gains in efficiency that can and should be made within the health sector (especially in the realm of administration and management), until the most serious systemic barriers to care-seeking are properly alleviated, improvements in health outcomes will continue to occur at a much more modest rate than would otherwise be possible. To its credit, the Ministry has made a noticeable push to improve staffing levels within facilities, but such improvements cannot stop there. Continued improvements in drug supplies and the building of health facilities must be prioritized, along with meaningful funding for health education outreach efforts at the community level, which can alleviate some of the barriers to access that are brought on by long distances.
2. **Timely remittance of emoluments of Health Workers:** It is important for policy makers to appreciate the role of timely payment of health workers. Instances in which health workers go without remuneration for months on end must stop, and district technical and political leaders need to mobilize whatever political muscle is necessary to ensure that it does. Health workers also mentioned cases in which, after having gone for months without pay, remuneration would suddenly begin again, but would not include compensation for time worked during months when emoluments disappear. Study participants unanimously believed that what happens to such money ought to be a subject of investigation. If individual districts show little interest in pursuing these issues, civil society organizations—with the help of the media—should step in.
3. **Prioritize Districts with Few Health Facilities per Capita for Infrastructural Improvements:** Some districts have more health facilities per capita than others. In districts where facility coverage is relatively low—which means that a larger proportion of the population must rely on fewer numbers of facilities—ensuring that those facilities are well stocked and supported with sound infrastructure becomes extremely important. Additionally, in instances where a single facility must cover a wide geographical area, ensuring that that facility is well outfitted could go far in encouraging caretakers to seek its services in a timely manner, despite some of the hardships associated with

transportation and physical access. As some caretakers made clear during the study, the perception of low drug stocks and inadequate infrastructure deters a number of people from "gambling" on public facilities in the first place.

4. **Issue Policy Directives that Require Health Workers to Treat Children under Five Who Live Outside a Facility's Catchment Area:** Ensuring that the health of children under five is prioritized throughout the country means allowing caretakers to visit facilities outside their respective sub-counties and districts when seeking services for young children. Given the hardships related to distance that many families must endure, allowing caretakers that reside outside a given area to seek treatment at the nearest facility should be a policy priority of the Ministry of Health, even if that facility is not located within the caretaker's precinct. To implement such a policy will also require additional resources to those facilities that can document that a certain to-be-determined proportion of the services they offer go to children who reside outside the facilities' designated geographical catchment areas.

5. **Integrate Men in Health Education Outreach Efforts Related to Children under Five:** As the findings on gender show, men are often involved in decision-making about care-seeking on behalf of children under five. Because of this, they should be included in all health-related outreach efforts undertaken through health facilities and NGOs. Oftentimes, women are prioritized in such efforts, usually because of their outsized role in the physical care provided to small children. However, given the involvement of many men in financing treatment, and even determining where and when to seek medical care, they cannot be deprioritized during health-related outreach initiatives designed to sensitize caretakers on ways to improve the health of children under five.

6. **Prioritize Quick Wins within the District:** Within Uganda's health system, there exist a number of quick wins that district leaders can and should prioritize. Policies to strengthen queue management, for instance, could go far in ensuring that children who come to public health facilities in critical condition are prioritized for care. Similarly, serious commitments to crack down on abusive behaviour and the solicitation of illegal fees ought to be prioritized. However, as with many desirable managerial improvements in service provision, prioritizing such changes is one thing; implementing them quite another. Although on the surface they appear to be "low-hanging fruit"—cheap to implement relative to other supply-side interventions such as ending the problem of stock-outs—they pose additional challenges that are linked to incentives such as pay and whether it is adequate and timely, and whether supervisors are facilitated and prevailed upon to carry out their functions.

7. **Publicize Efforts at Improving Service Provision:** The Ministry has made a number of investments over the past couple years to improve the quality of services provided within public health facilities. The hiring of more health workers is perhaps one of the most consequential of these investments. However, long periods of time in which public facilities have been inadequately staffed have allowed negative perceptions of public provision to take root. Efforts to bring about much-needed change therefore require not simply laying the ground for improving service quality, but public sensitization campaigns that inform end-users about what is being done and, consequently, what they should expect and not expect, let alone accept, when they go public health facilities in search of care. Such campaigns would also put health workers on notice regarding what, in terms of their personal conduct, they should not expect to get away with. This is likely to curtail the rampant abuse that members of the public suffer along with health workers' sense of impunity.

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Appendices

Socio-Demographic Profile of Focus Group Discussion Participants

Demographics	120 participants in FGDS located 3-5 km from nearest facility	119 participants in FGDs located 5-7 km from nearest facility	118 participants in FGDs located 8-10 km from nearest facility	Total
Age				
15-24	32	29	18	79
25-34	55	55	69	179
35-44	25	25	20	70
45+	7	8	11	26
Age not given	1	2	0	3
Average number of living children per woman	4	4.5	4.3	--
Education				
None	7	7	10	24
Primary	87	89	89	265
Secondary	21	17	18	56
Tertiary	0	0	0	0
Education not given	5	6	1	12
Occupation				
Farming	109	111	103	323
Housewife	6	3	4	13
Commerce/Trade	3	2	10	15
Other	2	3	1	6

Baseline Study Guides/Protocols

Focus Group Discussion Guide

I. Introduction - [1 minute]

Welcome and thank you for taking time to participate in this discussion today. My name is [MODERATOR] and this is [NOTE-TAKER] and we are working on behalf of the Advocates Coalition for Development and Environment (ACODE) for a project supported by the Ministry of Health. We're here to understand better the challenges that parents and caretakers of children under the age of 5 face when it comes to the health of their children. Your comments and those of other participants will help us create strategies to improve health services for children under five in [DISTRICT].

II. Ground Rules - [1 minute]

We are interested in all of your opinions and feelings. There are no right or wrong answers. We need your ideas, including any criticisms you may wish to express. We encourage you to be frank in your comments because it is important for our study. Some of you may agree or disagree with each other. That is perfectly normal. So do not feel shy to share your ideas openly. Do not wait for the moderator to ask for your opinion; feel free to speak at any time. However, please try to avoid interrupting others while they are talking. Everyone will have a chance to speak and all ideas, concerns, and opinions are of value. The session will last approximately 1 to 1.5 hours.

III. Confidentiality - [1 minute]

Everything said in this room is confidential. We will not tell anyone that you participated in this discussion. All the information that we collect is kept in confidence by our office, ACODE. A tape recorder will record what is said so that we have an accurate account of your views. However, we will never use your name in any reports we write. My partner will also take some notes to help us in this task. Do you have any concerns about the discussion being tape-recorded? Does anyone have any questions?

IV. Introduction of Participants (Warm-Up) - [2 minute]

We would like each of you to introduce yourself. Also, please tell us how many children you have and how old your youngest child is.

V. Expectations and Fears (Warm-Up) – [3-5 minutes]

Do you have any questions about this focus group discussion?

THEMES	QUESTIONS	PROBES
Most common health problems affecting children in the community?	• What health problems do you most worry about? Why? • What health problems affect children under 5 years most in your community?	• If diarrhoea, pneumonia, and malaria are not mentioned: How about [diarrhoea, pneumonia, malaria]—are they common also? What causes [diarrhoea, pneumonia, malaria] in young children?
CHILDHOOD ILLNESSES: DIARRHOEA, PNEUMONIA, AND MALARIA		
Initial utilization: barriers to initial use of/access to medical facilities	• What do parents in this community do when their children are sick? (Diarrhoea, Malaria, Pneumonia) • Where do you seek treatment when your child is sick with diarrhoea, malaria, or pneumonia): o A relative? o Pharmacist / drug seller / shop? o VHT? o Public health facility? o Private doctor or nurse/ paramedic? o Traditional healer? o I look for and use herbs. • Do some families fail to provide treatment outside the home when they want it? Why? Do their children get treated in other ways? Please explain.	• Are there other things that parents would like to do when they think their children are sick, but do not for some reason? [If yes] What are they? Why don't they do these things?

THEMES	QUESTIONS	PROBES
Continuous utilization: barriers to continuous usage of a treatment in response to child's visit to a VHT or facility.(Includes issues of access to services at health facilities, access to information, health care providers.)	• [If VHTs are mentioned; if not, probe] Do VHTs help when your child is sick? • [If facilities are mentioned; if not, probe] Do you have access to PUBLIC health facilities in your area? Yes/ No. • What is your experience with public health facilities when your child is sick? • If price is mentioned, is it costly to treat children when they have diarrhoea, pneumonia, or malaria? What are the costs of treating a child? Please explain.	• Can health care providers help you when you need help? Is there anything you wish they'd do that they currently don't?
Quality: barriers to completing a treatment within a proscribed timeframe	• How do parents know when the child is getting better? What are the first signs that show that the child is getting better? • If you've ever received medicine for your child's illness, when do you stop giving medicine? • [If they've ever gotten medicine to treat a childhood illness] Is timing important when taking medicine for a child's illness? ○ PROBE: Is it important <u>when</u> a child gets treatment? • How do you tell that it is time to give the next dose to your child?	

THEMES	QUESTIONS	PROBES
MALE INVOLVEMENT		
Male involvement in family health-seeking behavior	• What do fathers / husbands in this community do when one of their children falls sick? ○ Who decides when and where to take children when they fall sick?	
IMMUNIZATIONS		

Attitudes toward immunization	• Do parents in this community get their children immunized?
	  ○ Why or why not?
	• How do parents feel about immunizations?
	• Are there questions about immunisation that you want answered but have never asked anyone?
	  ○ If so, how come you have never asked?
	  ○ If you have asked, what happened? Did you find the answer helpful?
	• Would you say that health workers help you understand what immunization is about? Why or why not?
	• Do some parents not immunize for other reasons?
	• Does anyone here ever worry that health workers will do things that you may not want them to do?
	  ○ Do other parents worry?
	  ○ If so, what kind of things are they/could they be?
		• Fears or concerns about immunizations?
		• How do health workers treat you?

THEMES	QUESTIONS	PROBES

General attitudes towards disease testing	• Do health workers ever give your children blood tests before treating them?
	  ○ [IF YES] for which diseases?
	  ○ How do you feel about that?
	• Do you ever worry that your children might be tested for diseases that you don't want them tested for? Do other parents worry about it?
	  ○ [IF YES] for which diseases?
	• What do parents do about it?	

HEALTH SERVICES		
Availability and access	• What kinds of health units are available in your community? • Do you prefer to go to particular health units when your child is sick? • How do you get to different health units?	• Health units: probe for public clinics drug shops, traditional health services • Transportation: probe for type, availability, and cost
Perception of the quality of health services **Quality of health workers**	• What is your experience with VHTs in your community? • How do health workers treat you?	• Are facilities helpful? Are there times when they're not helpful?
Public versus private facilities	• Do parents in this community seek services from private facilities? • Are there differences in the quality of care between public and private facilities? Differences in cost? • Do you like to go to private facilities or public facilities?	• Who goes to private facilities? Who goes to public facilities?

THEMES	QUESTIONS	PROBES
How could quality of health services be improved? **User satisfaction?** **Community demand for services / accountability?**	• What do you have to say about the quality of health services available in your community? ○ [If complaints are voiced]: What can make the quality of health services better? • Are there things that you wish were different? If so who should do it? • Do you feel you have the capacity to influence the posting of health workers?	
RANKING		
Ranking barriers to care	• As a group, I'd like you to rank the five biggest challenges that parents and caretakers face in your community when they try and seek health care for their children. *Have group rank in order, with one being the greatest barrier to seeking care.*	• These should be the top five things that may cause some parents to delay taking their children for treatment.

In-Depth Interview Guide for Caretakers of Children under Five

I. Introduction - [1 minute]

Good morning/afternoon. My name is [INTERVIEWER]. Thank you for taking time to participate in this interview today. I am working on behalf of the Advocates Coalition for Development and Environment for a project supported by the Ministry of Health. I'm here to understand better some of the challenges that you may face as a parent of children under the age of 5 when it comes to the health of your children. Your comments will help us create strategies to improve health services for children under five in [DISTRICT].

II. Ground Rules - [1 minute]

I am interested in your opinions and feelings. There are no right or wrong answers. I need your ideas, including any criticisms you may wish to express. We encourage you to be frank in your comments because it is important for our study. Do not wait for me to ask for your opinion; feel free to speak at any time. This interview will last between 45 minutes to one hour.

III. Confidentiality - [1 minute]

Everything said during this interview is confidential. I will not tell anyone that you participated in this discussion. Everything that you say is kept in confidence at our office, ACODE. A recorder will document what you said so we have an accurate account of your views. However, we will never use your name in any reports we write. Do you have any concerns about the discussion being tape-recorded?

Do you have any questions for me before we start the interview? If you have any additional questions or if you want to get more information about this study, you can contact our project director Elizabeth Allen at 0787-621-132.

Do you have any questions for us?

IV. Introduction of Interviewee (Warm-Up) - [1 minute]

Can you introduce yourself? Also, please state how many children you have and how old your youngest child is.

V. Expectations and Fears (Warm-Up) – [2 minutes]

Do you have any questions about this interview?

District:	
Supervision Area:	
Sub-county:	
Village:	
Name of the mother (optional):	
Age:	
Number of children ever born:	
Education level:	
Occupation:	

THEMES	QUESTIONS	PROBES
General	• What health problems do you most worry about? Why? • What health problems affect children under 5 years most in your community? • Have you had to deal with these problems with your own children? ○ How has that been?	• If diarrhoea, pneumonia, and malaria are not mentioned: How about [diarrhoea, pneumonia, malaria]—are they common also? What causes [diarrhoea, pneumonia, malaria] in young children?
CHILDHOOD ILLNESSES: DIARRHOEA, PNEUMONIA, AND MALARIA		

Differences in care-seeking behavior	• What do you do when your children are sick? What do other parents do?
	• Which of these illnesses worries you most: diarrhoea, pneumonia, and malaria?
	  ○ What do you do when your child catches the illness that worries you most?
	  ○ What do you do when the child catches one of the others?	

THEMES	QUESTIONS	PROBES
Initial utilization: barriers to initial use of/access to medical facilities	• Do you seek treatment outside the home if your child is sick? • Where do you seek treatment when your child is sick with diarrhoea, malaria, or pneumonia): ○ A relative? ○ Pharmacist / drug seller / shop? ○ VHT? ○ Public health facility? ○ Private doctor or nurse/paramedic? ○ Traditional healer? ○ I look for and use herbs. • Are there times when you are not able to get treatment outside the home when you want it? Why? Do your children get treated in other ways? Please explain.	• Are there other things that you would like to do when you think your children are sick, but do not do for some reason? [If yes] What are they? Why don't they do these things?
Continuous utilization: barriers to continuous usage of a treatment in response to child's visit to a VHT or facility. (Includes issues of access to services at health facilities, access to information, health care providers.)	• [If VHTs are mentioned; if not, probe] Do VHTs help when your children are sick? • [If facilities are mentioned; if not, probe] Do you have access to PUBLIC health facilities in your area? Yes/No. • What is your experience with public health facilities when your child is sick? • If cost is mentioned, is it costly to treat children when they have diarrhoea, pneumonia, or malaria? What are the costs involved?	• Can health care providers help you when you need help? Is there anything you wish they'd do that they currently don't?

THEMES	QUESTIONS	PROBES

Quality: barriers to completing a treatment within a proscribed timeframe	• How do mothers know when the child is getting better? What are the first signs that show that the child is getting better?
	• If you've ever received medicine for your child's illness, when do you stop giving medicine?
	• [If they've ever gotten medicine to treat a childhood illness] Is timing important when taking medicine for a child's illness?
	  ○ How do you tell <u>when</u> it is time to give the next dose to your child?
	• Have you always done things this way?
	• Are there things you've learned over time that help you care for your children?
	  ○ IF YES: Can you tell us about what you've learned?
	  ○ Are there any experiences you've had that have helped you learn how to care for your children?	

MALE INVOLVEMENT		
Male involvement in family health-seeking behavior	• What do fathers / husbands in this community do when one of their children falls sick? ○ Who decides when and where to take children when they fall sick?	

THEMES	QUESTIONS	PROBES
IMMUNIZATIONS		
Attitudes toward immunization	• Have all your children been immunized? ○ Why or why not? • How do you feel about immunizations? • Are there questions about immunisation that you want answered but have never asked anyone? ○ If so, how come you have never asked? ○ If you have asked what happened? Did you find the answer helpful? • Would you say that health workers help you understand what immunization is about? Why or why not? • Do you ever worry that health workers will do things that you don't want them to do? ○ If so, like what?	• Fears or concerns about immunizations? • Do health workers answer your questions? • How do health workers treat you?
General attitudes towards disease testing	• Do health workers ever give your children blood tests before treating them? ○ [IF YES] for which diseases? ○ How do you feel about that? • Do you ever worry that your children might be tested for diseases that you don't want them tested for? ○ [IF YES] for which diseases? • What do you do about it?	
HEALTH SERVICES		
Availability and access	• What kinds of health units are available in your community? • Do you prefer to go to particular health units when your child is sick? • How do you get to different health units?	• Health units: probe for public clinics drug shops, traditional health services • Transportation: probe for type, availability, and cost

THEMES	QUESTIONS	PROBES
Perception of the quality of health services **Quality of health workers** **Public versus private facilities**	• What is your experience with VHTs? • What about public facilities in your community: are they helpful? • How do health workers treat you? • Do you ever seek services from private facilities? • Do you like to go to private facilities or public facilities?	
RANKING		
Ranking barriers to care	• What are the five biggest challenges that you face, as a parent, when you try to seek health care for your children? *Have person rank in order, with one being the greatest barrier to seeking care.* • What do you do when these challenges come up?	• Has anything bad ever happened because of these challenges?
QUALITY AND SATISFATION		
How could quality of health services be improved? **User satisfaction?** **Community demand for services / accountability?** **What can make planning and implementation better?**	• What do you have to say about the quality of health services available in your community? ○ IF COMPLAINTS ARE RAISED: What can make the quality of health services better? • Are there things that you wish were different? If so, who should do it? • Do you feel you have the capacity to influence the posting of health workers? • Are there other things that you would like to talk about regarding this topic?	

Key Informant Interview Guide for Health Care Professionals

Target: In-Charge and MCH Health Worker

I. Introduction - [1 minute]

Thank you for taking time to participate in this interview today. My name is [INTERVIEWER] and I am working on behalf of the Advocates Coalition for Development and Environment (ACODE) for the CODES project. You may already be familiar with CODES. But if you're not, CODES is a multi-year effort developed by the Ministry of Health in partnership with UNICEF, my organization ACODE, and ChildFund International. CODES stands for "Community and District Empowerment for Scale-up." The goal of CODES is to support and strengthen the Ministry's and district's strategies for child survival.

In keeping with that goal, I'm here today to understand better some of the challenges that you've seen as a health care professional serving parents and caretakers of children under the age of 5. Your comments will help us create strategies to improve health services for children in [DISTRICT].

II. Ground Rules - [1 minute]

I am interested in your opinions and assessments. There are no right or wrong answers. I encourage you to provide frank comments that will improve our work. This interview will last between 45 minutes to one hour.

III. Confidentiality - [1 minute]

Everything you say is kept in confidence at our office, ACODE. If you consent to it, a recorder will document what you say so we have an accurate account of your views. While we will never use your name in any reports we write, it may be possible for individuals at the district level to identify you, given the fact that we will be interviewing a small number of health workers in [DISTRICT]. However, our questions mainly focus on care-seeking behavior among parents and caretakers of children under five. We will not ask you to comment on the management of health services at the district or national levels. Do you have any concerns about the discussion being tape-recorded?

Do you have any questions for me?

IV. Introduction of Interviewee (Warm-Up) - [1 minute]

Can you introduce yourself? Also, please state your occupation, how many years you've served in that role, and the health facility to which you are attached.

District:	
Supervision Area:	
Sub-county:	
Village:	
Name:	
Title:	
Health Facility:	

THEMES	QUESTIONS	PROBES

General	• What are some of the biggest health problems that affect children under 5 years in this area?
	• Are there unique challenges that exist within your district, when compared with the rest of the country?
	  ○ Within the population?
	  ○ Geography?
	  ○ History?
	  ○ Health facilities?
	• What are some of the challenges you face as a [ROLE/TITLE] at this facility when it comes to treating children?	

THEMES	QUESTIONS	PROBES
CHILDHOOD ILLNESSES: DIARRHOEA, PNEUMONIA, AND MALARIA		
Utilization of services	• When it comes to diarrhoea, pneumonia, and malaria, which of the three ailments has been most challenging for the facility to deal with, and why? • Are there things you would like to do when it comes to treating these three ailments that you aren't able to do? If so, what are they, and why?	
MALE INVOLVEMENT		
Male involvement in family health-seeking behaviour	• What do fathers / husbands in this community do when one of their children falls sick? ○ Who decides when and where to take children when they fall sick?	
HEALTH SERVICES		

Quality of services	• Based on your experience, where do parents usually seek treatment when their children are sick with diarrhoea, malaria, or pneumonia):
	  ○ A relative?
	  ○ Pharmacist / drug seller / shop?
	  ○ VHT?
	  ○ Public health facility?
	  ○ Private doctor or nurse/paramedic?
	  ○ Traditional healer?
	  ○ Herbs?
	• Can you comment on the quality of pharmacists/drug sellers/shops in this area?
	• Can you comment on the quality of different private services in this area?
	• Is it generally true that the poorest of the poor rely on public facilities?	

THEMES	QUESTIONS	PROBES
Parents' perceptions of facility	• Based on your expertise, how do parents perceive health services at this facility? ○ Why do parents perceive services in this way? ○ Are these perceptions accurate? • IF PERCEPTIONS ARE NEGATIVE: What can be done to change these perceptions?	• Are there particular complaints that you hear from community members about health care at this facility? ○ Are those complaints fair?
Parents' perceptions of health workers	• Based on your professional experience, how do parents perceive health workers at this facility? ○ IF PROBLEMS ARE MENTIONED: Are there things you would like to do to improve things, but haven't been able to do? If so, what things, and why?	○ IF PROBLEMS ARE MENTIONED: Are these complaints fair?
Health worker challenges	• What challenges do health workers face in this facility? • Are there things that could be done to help health workers?	
VHTs	• What is your opinion of the VHTs who operate in this area? ○ Are VHTs helpful in this area? • Are there any changes that you would like to make when it comes to VHTs, but can't? If so, why?	• Do you oversee any VHTs?
IMMUNIZATIONS		
Attitudes toward immunization	• What are the challenges to immunizing children in this area? ○ PROBE: attitudes of parents towards immunizations in this community? • Are there things that you would like to do, but aren't able to do, when it comes to immunizations in this area?	

THEMES	QUESTIONS	PROBES

General attitudes towards disease testing	• What is this health facility's policy towards testing children for HIV/AIDS?
	  ○ How has the policy worked so far?
	• Do some parents ever worry that their children might be tested for diseases that they don't want them tested for?
	  ○ [IF YES] Does this ever have an effect on some parents' willingness to bring their children to the health center to be treated?	

RANKING		
Ranking barriers to care	• What are the five biggest challenges or barriers to care that parents of children under five face when they try to seek health care for their children? *Have person rank in order, with one being the greatest barrier to seeking care.* • Given your role at the facility, is there anything you can do that would have an affect on these challenges or barriers? ○ Are there things that you would like to do, but can't do for some reason?	
SATISFATION		
How could quality of health services be improved? **User satisfaction?** **What can make planning and implementation better?**	• What do you have to say about the quality of health services available in your community? ○ IF CRITIQUES ARE VOICED: Can services be improved to help health workers address the needs of patients? • Are there other things that you would like to talk about?	

Verbal Informed Consent Form

Your Part in the Study

If you agree to participate in the study the discussion will take about one hour. By taking part in this discussion/interview, you consent to being a participant in this study.

If You Decide Not to Participate in the Study

Your participation in the study is voluntary and there is no penalty for refusing to take part. If you do not wish to participate, you may stop at any time. There will be no cost to you as a result of participating in this study.

Confidentiality

The information you provide will be confidential. Responses will be completely anonymous, your name will not appear anywhere in the final write up of the research findings.

Benefits

There will be no direct personal rewards from participating in the study. However, you will receive a transport refund of 5,000 shillings.

Risks or Discomfort

People will respond to questions differently, and you may feel uncomfortable with some questions that we will ask. If you experience any personal discomfort during the discussion you may, as stated above, ask to move on to another question or stop the discussion (withdraw from the study) at any time.

Contact Person for Questions

If you have any questions about the study or any problems with the study you may contact Elizabeth Allen, who oversees the study, at the following telephone number: 0787-621-132.

Thank you again for your participation.