

**Exploring Caregivers' Trust in Community Health Workers in Rural Uganda**

by

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# Abstract

The purpose of this qualitative study is to gain a better understanding of the type of trust, and what factors influence the trust community members have in community health workers (CHWs) serving their communities in rural Western Uganda. Trust is a complex concept that has been widely recognized as important in patient-provider relationships, and has been found to positively influence health seeking behaviours as well as generate positive health outcomes. Trust within the health sector is a relatively new research area, with most of the current literature focused on relationships between patients and nurses or doctors in middle to high income countries. In developing countries, a large proportion of the population do not have access to nurses or doctors because of a shortage of skilled health workers. As a result, CHW programs have been developed to improve access to health services to rural and remote communities, where most of the population tend to live. CHWs are often the first point of contact with the health system for rural communities, but there is limited literature exploring the role or extent of trust in CHWs.

Semi-structured interviews were conducted with caregivers of children under five years of age in Kyenjojo District, western Uganda to explore the type of trust and factors influencing their trust in CHWs providing medical services to children under five. Interviews were guided by a conceptual framework based on a model of trust in health providers in high resource settings. The findings indicate that some dimensions of trust identified in high resource medical relationships also apply in this low-resource context, such as perceived provider loyalty and competence. Authority figures reinforced perceived CHW competence and a strong emphasis was placed on interpersonal relationships and broader community-CHW interactions, such as

reputation and word of mouth as important factors in the development of trust between caregivers and CHWs.

## **Preface**

This thesis is an original work by Elizabeth Yue. The research project, of which this thesis is a part, received research ethics approval from the University of Alberta Research Ethics Board, Project Name “Exploring mothers' trust in community health workers in rural Uganda”, Pro00057972, July 19, 2015; from the Makerere University School of Public Health – Higher Degrees, Research and Ethics Committee, Project Name “Exploring mothers' trust in community health workers in rural Uganda”, HDREC 325, August 19, 2015; and from the Uganda National Council for Science and Technology, Project Name “Exploring mothers' trust in community health workers in rural Uganda”, SS 3910, September 22, 2015.

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## **Abbreviations**

**ACT:** Artemisinin combination therapy

**CHW:** Community health worker

**iCCM:** Integrated community case management of childhood diseases

**MoH:** Ministry of Health

**ORS:** Oral rehydration salts

**RDT:** Rapid diagnostic tests

**VHT:** Village health team

# Chapter 1: Introduction

This thesis is based on a study examining the extent of and the factors influencing trust that caregivers of children under five years old have in community health workers (CHWs) trained to treat uncomplicated cases of malaria, pneumonia and diarrhea in rural Uganda. Although the importance of trust in effective patient-provider relationships has been recognized for some time, research in this area is relatively recent, with the majority of studies looking at trust between patients and medically trained staff in the USA or other high income countries.<sup>1</sup> Trust has shown to be an important factor influencing many therapeutic processes, such as patient acceptance of and adherence to therapeutic recommendations, as well as satisfaction with medical care.<sup>2-5</sup>

Many low-income countries face a shortage of skilled health workers. As a result, CHW programs have been developed to improve access to health services in rural and remote communities by training local community members to provide essential basic medical services.<sup>6</sup> CHWs often act as the first point of contact with the health system in many rural communities. In Uganda, the WHO and UNICEF backed integrated community case management (iCCM) strategy has been adopted to combat the unnecessary number of childhood deaths in children under five years. Under iCCM, a team of CHWs are trained to diagnose and treat children who have malaria, pneumonia or diarrhea.<sup>7</sup> Studies on trust in these types of health providers is limited. This study is a qualitative research project in which 28 rural primary caregivers of children under five in Kyenjojo District were interviewed to explore the trust they have in CHWs working under the iCCM strategy. Specifically, this research assesses community member perceptions of important dimensions of trust and the factors that influence their trust in CHWs.

## **1.1 Statement of the problem**

Poor trust or difficulties in establishing a strong trusting relationship between CHWs and caregivers of children may diminish the effectiveness of rural CHW-based programs. Since trust is a significant issue in health seeking behaviours and treatment adherence, there is value in researching what trust exists in CHW-based health settings in low-income countries, and what influences the trust community members have in their CHWs.

## **1.2 Justification of the problem**

With a better understanding of trust in this setting, programs can be improved by facilitating increased trust in CHWs. Improving trust could thus lead to better health seeking behaviours or improved adherence to treatment, and thus better health outcomes in the community.

## **1.3 Background**

Uganda is a country in East Africa, bordered by Sudan in the north, Kenya in the east, Tanzania and Rwanda in the south and the Democratic Republic of Congo in the west. Uganda is divided into 111 districts. English is the official national language, however there are numerous Niger-Congo languages spoken throughout the country. In the Kyenjojo District, where data collection took place, the primary language spoken is Rutooro.<sup>8</sup>

Demographically, Uganda has a total population of around 36 million with a 3.3% population growth rate between 2010-2015.<sup>9</sup> The majority of the population (84%) live in rural areas, with a life expectancy of 58.7 years.<sup>10</sup> Uganda's population is very young; almost half of the population (49%) is under the age of 15, with 18.5% of those being under-five.<sup>10</sup> The under-five mortality rate, which is the probability of dying between birth and five years of age per 1,000 live births, is 69, which ranks Uganda at 39th in the world.<sup>10</sup> The estimated Gross National Income per capita in the year 2013 was \$681 USD (approximately \$695 CAN).<sup>9</sup> Several studies in Uganda show unacceptably high mortality rates from preventable diseases such as malaria, pneumonia and diarrhea, particularly in children under five years old.<sup>11,12</sup> These high mortality rates can be explained in part by the low rates of treatment for these illnesses. In 2010, the Uganda Ministry of Health (MoH) stated that 33 million cases of malaria, pneumonia and diarrhea go untreated every year.<sup>13</sup>

### **1.3.1 Health care in Uganda**

#### **1.3.1.1 Structure of Uganda's health care delivery**

In Uganda, the formal health care system consists of various levels of health centres (HCs) and hospitals at district, regional and national levels (Table 1). Starting with the Health Centre I at the village level, CHWs work out of their homes and carry out basic health promotion and preventative and curative services for malaria, pneumonia and diarrhea. HC-IIIs are located at the parish level, and are the first level of interaction between health professionals and communities. HC-IIIs only provide outpatient services through a comprehensive nurse, who also supervises CHWs. HC-IIIs are at the sub-county level and provide outpatient services, as well as

maternity services and inpatient care, and support the community and HC-IIs in its jurisdiction. At HC-IIIs, the highest cadre of staff is a clinical officer. At the county level, HC-IVs provide inpatient care, maternity services and supervise the lower units, and the highest cadre of staff is a medical doctor. District hospitals provide basic care as well as surgery, laboratory and medical imaging services and blood transfusions. The Regional and National referral hospitals provide specialist clinical services, higher levels of surgical and medical services and are involved in health research and teaching.<sup>14</sup>

Political turmoil in the 1970s and 1980s led to the collapse of the publicly-funded health care system, leaving a gap for the private sector to fill. About 60% of the hospitals and health centres are run by the government, while the rest is run by the private sector; either not-for-profit or private-for-profit.<sup>15</sup> There are also a plethora of unrecognized small private clinics, drug shops and informal health providers such as traditional healers.

**Table 1: The structure of the health system in Uganda**

<b>Location</b>	<b>Health Structure</b>	<b>Services</b>
<b>Village</b>	HC-I	Basic health promotion and outreach services by CHWs.
<b>Parish</b>	HC-II	Outpatient and community outreach services only. Supervision of CHWs.
<b>Sub-county</b>	HC-III	Outpatient services, maternity, general ward and laboratory services. Supervision of lower HCs.
<b>County</b>	HC-IV	Outpatient services, wards, laboratory and blood transfusion services.
<b>District</b>	District hospital	Preventive, promotive, curative, maternity, surgery, blood transfusion, laboratory and x-ray services.
<b>Regional</b>	Regional referral hospital	Specialist services. Involved in teaching and health research.

Adapted from Government of Uganda, Health Sector Strategic Plan III, 2010/11-2014/15 <sup>14</sup>

### 1.3.1.2 Health care access in Uganda

Despite the implementation of many programs and efforts to improve health and access to health care over the past few decades, health and access to health care is poor in Uganda.<sup>16</sup> The health system faces multiple challenges which affect the quality of services, such as major inequities in access to health facilities and poor infrastructure. In some areas where infrastructure has been improved, challenges still remain due to inadequate or poorly maintained medical equipment.<sup>16</sup> Lastly, Uganda faces a large shortage of skilled workers which is a key limiting factor in providing appropriate health services to the population.<sup>16</sup> For example, in 2010 the density of physicians was estimated to be 1 per 24 725, a figure vastly below the WHO recommendation of 1 physician per 1 000 population.<sup>17</sup> The government of Uganda partly attributes the health worker shortage to inadequate numbers of staff, and skillsets. In addition, issues with remuneration, worker motivation, performance challenges, and lack of professional growth opportunities contribute to inadequacies in the health workforce.<sup>16</sup> Health staff attrition to private facilities or to other countries where the salaries are more competitive - in other words, a “medical brain drain” – is one consequence.<sup>17</sup> In addition, the skill level of existing staff is sub-optimal for treating a range of illnesses, particularly at rural health centres. Physicians and more highly qualified midwives and nurses are concentrated in urban areas because of higher pay, better living situations and better job opportunities.<sup>18</sup> Since the vast majority of the population live in rural areas, this translates into the majority of the population in Uganda receiving inadequate health care.<sup>17</sup>

Health facilities are often in poor condition, lack basic equipment and medical supplies, and drug shortages are common.<sup>16</sup> Rural medical workers are often faced with unmanageable workloads and little time off, which can affect their attitudes, behaviours and practices. Medical



workers have reported that when overworked, their tone of voice changes, and they are easily irritable due to fatigue and stress.<sup>15</sup> Long shifts and understaffing results in the inability for nurses to fulfill their professional role, which can lead to demotivation and a “don’t care” attitude towards patients. CHW programs have been implemented in Uganda as one way to help fill the gap in healthcare access. CHWs assist the formal health care system by providing timely and accessible basic health services to rural communities under the HC-I structure

## **Chapter 2: Literature review**

In this chapter I present a brief history of CHWs and programs in the global context, as well as the effectiveness of CHW programs for child health in low income countries. I then describe the CHW and iCCM approach in Uganda. Finally, I define the concept of trust, and examine the literature on trust in the healthcare setting, as well as trust in CHWs in low income countries.

### **2.1 Community health workers**

At the International Conference on Primary Health Care in 1978, the Declaration of Alma-Ata identified primary health care as the key to delivering Health for All.<sup>19</sup> The Declaration was the first global document recognizing primary health care, signed by all WHO member states present.<sup>19</sup> It formally recognized CHWs as part of the health workforce, and promoted the use of CHWs as a means to engage communities and to improve health care delivery of essential services.<sup>19</sup> With this push for primary health care in the 1970’s, CHWs were

endorsed as an effective means for populations to access comprehensive primary health care because of their ability to reach poor, rural populations who are less likely to access health facilities.<sup>20</sup> Spurred by the Alma-Ata declaration in the late 1970s, pilots for community-based primary health care and CHW programs were initiated and repeated over the following two decades.<sup>21</sup> In the 1990s, enthusiasm for CHWs decreased <sup>22</sup> but increased again in the 2000s.<sup>23</sup>

### **2.1.1 Who are CHWs and what do they do?**

Depending on the country and program, the terminology used to describe CHWs will differ. The umbrella term ‘community health worker’ describes lay individuals who are ideally selected by the community and are trained and work in health activities in the communities in which they belong.<sup>23</sup> As defined by Lewin et al., CHWs are:

“any health worker carrying out functions related to health care delivery, trained in some way in the context of the intervention, and having no formal professional or paraprofessional certificated or degreed tertiary education.”

Contingent on the cultural context in which they are situated, CHWs can be male or female, young or old.<sup>23</sup> Typically, CHWs have little formal educational background. While CHW training is not part of a certificate or degree, it may be recognized by the health services authority.<sup>20</sup>

Their roles and specific activities vary greatly from country to country and across programs; some CHWs perform a range of tasks that can be preventative, curative or developmental whereas other CHWs are chosen for specific initiatives.<sup>23</sup> Despite the vast array

of titles and CHWs programs, it is generally accepted that CHWs play a unique role in bridging the gap between formal health facilities and the communities, and are a vital part in improving health development and promotion of health services.<sup>23</sup> CHWs also have an important role in community engagement and empowerment over health-related problems, which can enhance community development and program sustainability.<sup>23</sup>

### **2.1.2 A brief history of CHW programs**

There is a long history of CHW programs worldwide. One of the most well known early programs is the Chinese barefoot doctor program, originating in the 1950s.<sup>24</sup> The barefoot doctors served at the village level after receiving short-term training, and provided basic health care and health education to the communities in which they lived.<sup>25</sup> Because of the short period of training compared to other health professionals such as physicians, and since barefoot doctors are from the villages in which they worked, this program was able to address the shortage of health providers in rural areas.<sup>25</sup> The success of the barefoot doctors program, coupled with the failure of the formal health system to deliver basic health care to all inspired other countries such as Honduras, India, Indonesia, Tanzania and Venezuela to experiment with early CHW programs in the 1960s.<sup>21,24</sup> There was a further proliferation of government CHW programs in the 1970s and 1980s in several Latin American countries as well as countries such as India, Indonesia, Nepal, Malawi, Mozambique and Zimbabwe.<sup>21</sup>

In the 1990s, enthusiasm for CHWs decreased because by then numerous national, top-down CHW programs had been created, typically with external support but unfortunately

without much success in sustainably scaling up the programs as had been envisioned at Alma-Ata.<sup>22</sup> In addition, other successful vertical programs such as immunization campaigns were competing with CHW programs.<sup>20</sup> However, in the 2000s, interest in CHWs was rejuvenated primarily due to the impact of the HIV/AIDs pandemic and the resulting shortage of professional health workers due to increasing workloads.<sup>23</sup>

Over the years, countless CHW programs have been implemented worldwide with many different CHWs providing a wide range of tasks. While there are too many to describe, CHWs can be broadly placed into one of two categories: generalist, or specialist CHWs. Generalist CHWs provide a very broad range of functions and do not focus on a specific group or disease; their activities can include house-calls, treatment of simple illnesses, family planning activities, health education, nutrition, referrals, and collection of data to name a few.<sup>23</sup> Not surprisingly, there is ongoing debate regarding how many jobs a CHW can realistically and effectively perform.<sup>23</sup> Perhaps as a response to the difficulty finding the best mix and scope of CHW functions, as well as responding to funding priorities, numerous CHW programs have focussed on specific health issues in the last 20 years.<sup>23</sup> A frequently mentioned area in the literature for specialist CHW programs is in maternal and child health.<sup>23</sup>

#### **2.1.2.1 CHW program challenges**

It has been shown that CHWs who are appropriately selected, trained, supervised and supported with constant supply of medicines and equipment are able to correctly identify and treat most children with pneumonia, malaria and diarrhea.<sup>26</sup> The issues with sustainable CHW programs however, lie in the varying factors within countries that prevent or limit such measures

from occurring. This includes corruption, poor coordination, funding issues and issues around maintaining CHW motivation, which will be discussed below.

In countries with weak political systems, decentralised, fragile management of health care can result in an unsupportive and difficult environment for CHW programs to succeed in. The possibility of corruption, where CHWs may be selected by politicians on the basis of their past support for local leaders is prevalent.<sup>20</sup> Unfortunately, even in countries where the practice of selecting CHWs from the communities is accepted, meaningful participation of the communities in that process is not always achieved. Studies have shown that in some situations, it is the local chiefs or health personnel who had the final say over who was selected.<sup>22</sup>

Another challenge CHW programs face is the prevalence of multiple, uncoordinated actors within a country when there is no strong guidance at the national level. In Sub-Saharan countries there are often many NGOs, faith-based providers, or other partners working in health with direct or indirect engagement with CHW programs.<sup>22</sup> These partners frequently work without national or local methods for coordination, and NGOs often have their own contracts for health workers. This combination can lead to the failure of providing equitable access to health services for all within a country due to a fragmentation of programs on the ground.<sup>22</sup> Additionally, NGOs often have to compete for funding, which can be a disincentive for them to cooperate with one another.<sup>22</sup>

Running out of funding is a common pitfall for unsustainable CHW programs. CHWs are typically not paid salaries, but they are often remunerated for their work in various ways. This can include preferential treatment at health facilities, and other non-financial incentives such as visual identification (t-shirts, badges etc.), gumboots and bicycles. Monetary honorariums are

often used and can increase CHW retention, however issues such as the amount of money not being satisfactory, or running out after external funding stops can result in a disincentive and lead to CHWs dropping-out.<sup>27</sup> It is important to note that if different CHW programs in close proximity to each other provide incentives that are quite different from each other, discouragement and de-motivation may occur in the volunteers. Some CHWs may not feel as appreciated for their efforts if they are not receiving the same remuneration as their peers who are working for a different CHW program. A weakened trust in the system may result.

Lastly, another main challenge CHW programs face is maintaining a consistent drug supply in often difficult situations. Having essential supplies in stock is key to a CHW program's success, especially when a child's prognosis depends on timely treatment. Frequent drug shortages place a strain on the CHW's ability to fully perform all their duties, and may negatively impact their standing in the community.<sup>20</sup> A decreased faith in the CHW program may result if drug shortages occur often, and people are consistently referred to the health facility, which are hard to access in the first place. Additionally, issues with drug distribution can be a demotivating factor if a CHW must travel significant distances to reach the health clinic where they are stored, only to find that they are not available.<sup>28</sup> All together, this may result in lower care-seeking behaviours among patients, lower CHW motivation, and reduced program effectiveness.

### **2.1.3 CHW programs for child health**

The leading causes of death for children under five are pneumonia (13%), malaria (7%) and diarrhea (9%) which together accounted for approximately 1.3 million deaths in Sub-Saharan Africa in 2013.<sup>7</sup> The international world recognized the importance of reducing these numbers globally, and addressed child health in the United Nations Millennium Development Goal (MDG) 4.<sup>7</sup> MDG 4 called attention to the need to reduce the global under-five mortality rate by at least two-thirds.<sup>20</sup> While considerable progress has been made in the last 2 decades, the majority of under-five mortality is still concentrated in the world's lowest income countries: Sub-Saharan Africa and Southern Asia accounted for 81% of child deaths in 2012.<sup>29</sup>

Childhood morbidity and mortality from these treatable and preventable diseases can be greatly reduced if appropriate care is sought early on, usually within 24 hours of symptom onset, thanks to the availability of relatively low-cost, life-saving technologies. Examples of easy to use treatments include oral rehydration salts (ORS), antibiotics for pneumonia, and antimalarials such as artemisinin-based combination therapies (ACT).<sup>26</sup> The key is to couple these effective medications with timely access.

Many CHW programs implemented in the last 20 years have focussed on specific health issues, and a frequently mentioned area for specialist CHW programs is in maternal and child health.<sup>23</sup> There is strong evidence that shows that CHWs can contribute to improved health outcomes in the field of child health.<sup>23</sup> UNICEF has documented seven general types of CHW intervention programs that focus on child mortality ranging from basic management and referral, to presumptive treatment of fever with antimalarials, to multiple disease case management.<sup>6</sup>

One program model called community case management (CCM) of childhood illnesses is defined as the community-level provision of treatment for diarrhoea, pneumonia and malaria by CHWs, and has been advocated by the WHO as a strategy to accelerate progress towards meeting MDG 4.<sup>23</sup> In 2010, a WHO survey explored CCM implementation targeting malaria, pneumonia, diarrhoea in 68 prioritized countries. Most of these countries were in Africa, where about 97% of maternal, neonatal and child deaths occur worldwide each year. This study found that around 88% of the 59 responding countries had a CCM policy for the child health conditions of interest.<sup>30</sup> The authors found a very strong association between CCM policy and implementation for malaria, a strong association for diarrhea, and a moderate association for pneumonia. In the malaria-endemic countries included, 75% had active policies for CCM, and 77% were actively implementing antimalarial CCM.<sup>30</sup> Evidence from this study reveals that CCM is a widely implemented strategy used in high child mortality settings.

#### **2.1.3.1 iCCM implementation to better address child mortality**

In 2004, WHO and UNICEF issued statements supporting community based clinical management of diarrhoea, pneumonia and malaria to curb child mortality.<sup>31</sup> Over the years leading up to then, programmatic experience and research has shown that separate community case management programs for malaria, pneumonia and diarrhea can reduce child morbidity and mortality in Sub-Saharan Africa.<sup>6,11,30,32,33</sup> What was noticed, however, was that most CHW programs manage a single disease, mainly malaria. Policy makers realized the possible limitations in impact that single-disease CHW programs may have since children may suffer from more than one illness at a time. For example, since malaria and pneumonia both have clinical presentations of fever, there is a large risk of many children being treated solely with



anti-malarial drugs, which may delay parents in seeking proper treatment at health facilities for pneumonia.<sup>26</sup> This could also result in inappropriate use of anti-malarial drugs when children with non-malarial febrile illnesses present with similar symptoms to malaria.<sup>33</sup> In recent years, the availability of easy-to-use, high quality rapid diagnostic tests (RDT) for malaria has made it possible to test for malaria at the community level, helping improve health workers' responses to febrile children.<sup>34</sup>

Because of the evidence supporting the need for better integration of services aimed at reducing child mortality, elements of the separate community-based services for malaria, pneumonia and diarrhea were combined into a strategy called integrated community case management (iCCM).<sup>26</sup> As recommended by the World Health Organization (WHO), iCCM is delivered by trained CHWs at the community level. The iCCM strategy encompasses CHW identification and immediate referral of newborns (0-28 days) with danger signs, and treatment of children under five for uncomplicated cases of:

- 1) RDT confirmed malaria with artemisinin combination therapy (ACT)
- 2) pneumonia with antibiotics, and
- 3) diarrhea with zinc and ORS.<sup>26</sup>

Promising evidence from a study in Uganda has shown that iCCM for pneumonia and malaria, increased prompt and appropriate treatment for pneumonia symptoms, and resulted in improved outcomes.<sup>33</sup> The iCCM program built upon existing community based strategies for treating malaria, such as the Home Management of Malaria (HMM). Under HMM, mothers were advised to bring children with fever to a community volunteer who was trained to distinguish signs of uncomplicated malaria from a more serious form of the disease. If the volunteers

deemed the condition serious, they would immediately refer the child to the nearest health centre; otherwise, the child was given anti-malarials.<sup>33</sup> Another study on the nationwide implementation of iCCM in Rwanda showed positive results. After successful implementation of a home-based management of malaria strategy, the Rwandan Ministry of Health expanded it nation-wide with the aid of external organizations and NGOs to include community case management for diarrhea and pneumonia.<sup>35</sup> Research showed that a year after implementation, under-5 mortality rate declined by 47% in 15 districts where baseline and comparison data was available.<sup>35</sup>

#### **2.1.4 CHWs in Uganda - the Village Health Team**

Limited geographical access to health care facilities in rural areas, coupled with an acute shortage of health workers is a key challenge for equitable access to health services in Uganda.<sup>24</sup> To address this challenge, in 2001 the Uganda MoH established a national Village Health Team (VHT) strategy to extend health service delivery to the entire population, in particular to rural areas.<sup>12</sup> The VHT is based in the community (at the village level) and VHT members (individual CHWs) are supposed to be selected by the same community in which they live and serve.

As described earlier in Table 1, VHTs serve as the Health Centre I, Uganda's lowest health delivery structure, to bridge the gap between underserved households and the formal health system.<sup>12</sup> The VHT government policy requires that all health activities at the community level (government, NGOs or other) be coordinated through VHTs.<sup>12</sup> The following criteria is suggested by the MoH to be used for VHT member selection:

- Should be exemplary, honest, trustworthy and respected
- Should be willing to serve as a volunteer
- Must be a resident of the village
- Should be available to perform specified VHT tasks
- Should be interested in health and development matters
- Should be a good mobilizer and communicator
- Ideally should be able to read and write at least the local language
- Should be dependable and approachable
- Should be a good listener
- Should be 18 years and above <sup>12</sup>

As laid out in the Uganda MoH VHT Strategy and Operational Guidelines, CHWs should be selected through a majority vote at a village meeting, called for by the Local Council 1 chairperson. The Local Council 1 chairperson is the elected government representative at the village level, and it is their responsibility to advocate for VHTs and to sensitize the community on the roles of the VHTs. They are in charge of informing residents of initiatives, such as the CHW program, and they are responsible for enforcing implementation of health related issues as recommended by the CHWs, and providing time for them to speak at community meetings, among other things.<sup>12</sup>

Political representatives such as the Local Council 1 chairperson are not eligible for CHW positions to ensure checks and balances. On average, five CHWs per village are selected and trained to carry out health promotion and education activities, each overseeing approximately 25-30 households. The training and technical responsibility of team falls under the health facilities where staff supervise the CHWs. The Uganda MoH VHT strategy mandates health facilities to honor referrals from CHWs and, when necessary, refer discharged patients to

CHWs for follow up in the community.<sup>12</sup> For the rest of the paper, VHT members in Uganda are referred to as CHWs to avoid confusion.

#### **2.1.4.1 iCCM in Uganda**

In Uganda, iCCM was introduced in 2010 by the MoH as a national strategy.<sup>13</sup> On average there are two iCCM CHWs per village, ideally selected by popular vote among the community members. The CHWs are subsequently promoted by the LC1 chairperson of that village, and are expected to introduce themselves and make their services known to those that may benefit. Typical iCCM training lasts for six days, after which the CHWs are provided with an iCCM kit including amoxicillin for non-severe pneumonia, ACTs for uncomplicated malaria, and ORS and zinc for diarrhea. In addition, CHWs are provided with diagnostic supplies such as rapid diagnostic tests for malaria and simple respiratory timers, as well as an iCCM patient record book to keep track of each patient treated.<sup>13</sup> To seek care, caregivers bring their sick children to the CHWs' homes, on a drop-in basis. While caregivers are encouraged to go to the CHWs as a first point of contact with the health system, there is no policy requiring them to.

## **2.2 Trust**

This study examined the extent of trust caregivers of children under five have in the iCCM CHWs in their village. Trust is an attitude that is generally understood as “an optimistic acceptance of a vulnerable situation in which the trustor believes the trustee will act in their best interests”<sup>36</sup> and combines expectations about the abilities or competence of the other person.<sup>37,38</sup>

Trust involves vulnerability and risk, where the motives and actions of another is uncertain and an individual must depend on another.<sup>36,38</sup> Trust in health care providers is a great example, as illness creates a need for physicians or other health care providers and so vulnerability, and trust, is unavoidable in medicine.

Using a well referenced approach outlined by Hall et al, in this study trust is examined by breaking the concept down into dimensions, and factors.<sup>36</sup> Dimensions of trust refer to what is trusted about someone, and which together form the construct of trust. Factors on the other hand influence the levels of trust one may have in an individual. The conceptual framework (see Chapter 3) lists the dimensions and factors of trust expected to be important in caregiver trust in CHWs.

Trust has a strong emotional quality because it involves having optimistic expectations of the trusted one's perceived motivations in an uncertain situation, such that the trusted one has your best interests at heart. This emotional component distinguishes trust from the concept of confidence, which refers to the objective prediction of positive results in a relatively stable situation.<sup>36</sup> When positive results are not achieved based on confidence, or objective assessments, it often results in disappointment. In contrast, the violation of trust often results in “an emotional reaction of moral outrage or indignation” because of the non-rational assumption of the trusted person's intentions.<sup>36</sup> Because of this reason, Hall et al., states “it is perfectly possible to trust an unskilled but very caring doctor or to distrust one who is highly competent but aloof”.<sup>36</sup>

Lastly, I would like to highlight the difference between trusting attitudes and trusting behaviours. Individuals may exhibit trusting behaviours, but that does not necessarily constitute

trust, especially in the context of health care delivery. In this context, trusting behaviours may be a result of their illness circumstances. It is important to remember that trust requires having a positive attitude, or optimistic expectations, as stated above. Someone may go to a certain health care provider because of necessity, but feel uneasy or pessimistic about the relationship or the encounter. So, while behaviours such as going to a health provider can indicate the possibility of trust, it is not always the case that trust exists.

### **2.2.1 Trust in the health care context**

Trust is widely recognized as important in patient-provider relationships, yet only in the past two decades have attempts been made to measure and analyze trust in the health sector.<sup>36,38</sup> Trust has been found to positively influence health seeking behaviours as well as generate positive health outcomes by encouraging patient disclosure.<sup>2-5</sup> Trust can strengthen the patient-provider relationship leading to co-operation in treatment.<sup>38</sup> As stated by Gilson, “trust is important to health systems because it underpins the co-operation throughout the system that is required for health production”.<sup>39</sup>

### **2.2.2 Types of trust**

Trust can be in the form of interpersonal, or institutional trust. Interpersonal trust is found between acquaintances, and is based on past experiences and interactions with each other. In contrast, institutional trust is based on generalised trust in the system, institutions or reputation, and is grounded in social norms which provide context for shared values.<sup>39</sup> Trust in institutions

such as health systems is formed by the establishment of some sort of basis to judge whether or not the individuals associated with them share your interests, or at least will not act in ways that will harm you.<sup>39</sup> Examples include disciplinary procedures promoting consistent behaviour, or institutional arrangements, such as the training and licensing of individuals. It is possible for both interpersonal and institutional trust to exist at the same time, and interpersonal trust can also act to reinforce institutional trust.<sup>40</sup> For example, in health care, a patient could trust their healthcare provider because of personal experiences with them, and because of their general trust in the health care system. Likewise, positive interpersonal trust relations between a patient and provider are important in sustaining and reinforcing trust in the broader health care system.

## **2.3 Trust in the healthcare setting in middle and high income countries**

The majority of literature on trust in the healthcare setting is found in middle to high income settings, with a focus on trusting relationships between patients and formally trained health providers such as nurses. Trust is a very important aspect of the nurse-patient relationship and is a widely discussed topic in nursing ethics literature because nurses are often the closest providers to patients, spending the most time with individuals at their most vulnerable.<sup>41</sup>

In their literature review on trust in the nurse-patient relationship, Dinc and Gastmans (2013) found 34 articles published between 1980 and 2011 that explored both the patients', and the nurses' perceptions of the importance of trust.<sup>42</sup> Studies in this review listed certain pre-conditions for trust formation in nurse-patient relationships, which are necessary conditions for trust to develop between patients and nurses. These studies reported that patients have a pre-

existing trust in nurses due to previous experiences, or a generalized trust in the health care system, and an initial trust in nurses due to their extensive training.<sup>42</sup> Other preconditions identified for trust development were the nurses' professional attributes such as technical competence, experience, good bedside manner, and continuity of service.<sup>42</sup> It was also found that getting to know one another as a person rather than as a patient / provider was important to the building of rapport, a pre-condition for a trusting relationship.<sup>43</sup>

In the review, nurses' personal qualities such as honesty, sensitivity, confidentiality, trustworthiness, and commitment to providing the best care were identified as important for the development of trust.<sup>42</sup> In addition, demonstrating genuine care and respect, acceptance of patients without prejudgement, empathy for patients' suffering, and providing good advice were important factors studies found to facilitate patient trust in nurses.<sup>42</sup> The importance of personal qualities is echoed in a review examining patient trust in physicians, where the authors state that the "strongest predictors of trust are physician personality and behavior" and that "patient trust is consistently found to be related to factors such as physicians' communication style and interpersonal skills".<sup>36</sup> Encouraging a parent's participation in their children's care was also found to be an important facilitator of trust in nurses.<sup>43</sup>

## **2.4 Trust in CHWs in low income countries**

Due to the shortage of skilled health workers in rural and low resource settings, CHWs frequently take on some of the roles of formal health care providers such as doctors and nurses. It would be important to understand whether individuals trust CHWs who taken on these broader



roles. Unfortunately, the literature around trust in CHWs, especially those who undertake diagnosis and treatment of children in the local community, is limited.

A search for published articles on trust in CHWs in low-income countries was conducted on Medline, Embase, Global Health, Psych Info, CINAHL, Scopus and Google Scholar using the following keywords and their variations: “trust” or “trusted” or “trusting”, “community health worker”, “community health aide” and “village health aide”. Only studies that focused on CHW-community member relationships in low-income countries were included. No date limit was set. In general, most of the published literature on CHWs in these settings focused more on a broader assessment of outcomes of programs, such as community acceptability of CHWs, CHW program implementation, and perceived quality of care of CHW programs, and only briefly touched on trust.<sup>44–46</sup>

Ten articles were found that studied CHW relationships with the community and which mentioned trust; these have been summarized in Table 2. All ten articles are based in rural settings; nine of them located in sub-Saharan Africa<sup>3,28,44,45,47–51</sup>, and one in India.<sup>46</sup> Five of the articles assessed the acceptability or feasibility of CHW based programs<sup>28,44,48,50,51</sup>; two assessed caretakers’ perceived quality of care of treatment by CHWs<sup>3,45</sup>, and one study explored the experiences of CHWs in a rural health program.<sup>46</sup> Eight of these studies, where trust was not the main focus, noted the importance of trust in patient-provider relationships and as an area requiring further investigation. However, there were two studies which had trust as their main research focus; one that looked at trusting relationships of CHWs between communities and the health sector<sup>49</sup> and another that examined mothers’ trust in CHWs in Ghana.<sup>47</sup> Themes around trust from these studies are outlined below.

One theme related to trust built around the use of technology. In two of the articles, the focus was the acceptance by the community of CHWs using rapid diagnostic tests (RDTs) to detect malaria in their children. The first, a qualitative study conducted in Sudan noted very briefly that trust in the technology of the RDT helped increase community trust in the CHWs, but did not elaborate any further on this topic.<sup>48</sup> The second qualitative study by Mukanga et al.<sup>44</sup> looked at community acceptability of the use of RDTs by Ugandan CHWs in a rural setting, and looked more deeply into trust in this context. In addition to questions about community willingness and acceptability of CHWs to use RDTs, the interview guide collected information on trust and confidence in CHWs. They found that community members reported trust in CHWs to manage fevers to be based on their past experiences of CHWs being accessible, helpful, and the recovery of their sick children after being treated by the CHWs. In addition, the education level of the CHWs proved to be a factor in trust, where those with lower education prior to becoming a CHW were viewed less favourably to be able to accurately use RDTs. Lastly, the study found that community perceptions of the CHW's commitment to voluntary service influenced community trust. However, the authors attributed CHW accessibility to caregiver trust, but behaviours such as visiting an nearby CHW does not necessarily equal trust (that is, trusting behaviors cannot be equated to trusting attitudes).

The role of institutional trust in patient trust in CHWs was noted in a few qualitative studies. Some villages in rural Uganda had a policy under which community members had to visit the CHW prior to going to the health centre, and Nanyonjo et al found that caregivers in these villages were more likely to visit the CHWs because of the perceived trust in CHWs from the health centres.<sup>28</sup> The role of community perceptions of the service-providing institution on trust in the CHWs was also echoed in a study by Mishra located in rural India, though their study

only involved health worker perceptions.<sup>46</sup> Finally, Pitt et al. assessed community perceptions of intermittent preventative treatment of malaria in children (IPTc) in Mali and Burkina Faso and noted that the social norms of these countries, such as trust in and respect for authorities, encouraged trust, respect and compliance in the IPTc program.<sup>51</sup> In this trial program, CHWs were hired to assist formal health care workers to administer tablets, and remind caregivers to attend sessions at the health clinic. Caregivers mentioned higher confidence in CHWs who were supervised by formal health workers, when asked about recommendations for drug distribution in the future.<sup>51</sup> These studies, however, did not explore clients' trust in the CHW (Mishra) or look any further into what else may have influenced client trust in CHWs (Nanyonjo et al). In the study by Pitt et al, the findings and focus of the study were geared towards formal health staff as they were the main providers of the health services in the IPTc program. While they found some caregivers to state a lack of confidence in CHWs who were unsupervised by health workers, the authors did not probe further into this aspect, or trust in CHWs.<sup>51</sup>

Another study in Uganda, explored the perceived quality of care of CHWs compared to health facility workers used a healthcare assessment survey.<sup>3</sup> In the survey, a trust summary scale was included as part of the domain measuring quality processes during a healthcare interaction, and asked patients to rank integrity, patience, and role of the health provider as the patient's agent.<sup>3</sup> Trust was reported as a mean value. This study found that trust plays a role in process measures for quality and, overall, the CHW's ratings were higher than those for the health facility workers. There was no further break down of the rankings for the single scale trust items, and no qualitative exploration of the level of trust seen.

A comparative analysis by Kok et al examined similarities and differences in the formation of relationships between CHWs, communities and the health sector in four Sub-

Saharan African settings: Ethiopia, Kenya, Malawi and Mozambique.<sup>49</sup> The authors identified the importance of trusting relationships between CHWs and the community, and studied the mechanisms that led to trusting relationships in certain contexts.<sup>49</sup> In three of the countries, it was found that CHWs who were from the area in which they served supported the development of trusting relationships between CHWs and community members.

One study looked at how trust influenced the utilization of health care services. A recent (2016) quantitative study by Muhumuza et al looked at access and utilization of iCCM services in rural Uganda and found a positive association between trust in the CHWs and the use of iCCM services. Respondents to their household survey indicated that trust in skills of the CHW and in the iCCM services were some reasons for seeking iCCM services.<sup>50</sup> The authors also mentioned how awareness of the iCCM services, through community sensitization efforts, increased trust in the services offered and thus increased the utilization of the services.<sup>50</sup>

Finally, one study by Buchner et al examined general perceptions of trust in CHWs and iCCM services.<sup>45</sup> The authors interviewed caregivers in addition to CHWs and health workers. They found that caregivers in the study expressed trust in the iCCM CHWs and services provided, through caregiver descriptions of their appreciation for the “trustworthy and caring” work and sacrifices they felt the CHWs made.<sup>45</sup> The authors do not elaborate further about the concept of trust, other than these statements.

In summary, the above-mentioned studies note that trust plays a role in the acceptability of community health workers, the feasibility of CHW program implementation in rural areas,

and in perceived quality of CHW programs. Individual CHW characteristics such as being caring and not having undesired behaviours, their education level, and perceived motivations were identified as influences on the trust the community has in them. Several studies discuss the role of one's trust in the institutions providing the services as well as in medical technologies such as the RDTs has on community member trust in the CHWs and CHW programs. However, none of the studies explored caregiver trust in CHWs in great detail. Most studies state that trust is important, but did not examine the concept of trust in a structured manner, and did not explore dimensions of trust that were relevant in these rural contexts. The importance of qualitative studies to explore the topic of caregiver trust is even more important, as trust is subjective and all aspects might not be captured in a pre-set survey. Based on the available literature there is a lack of an in-depth qualitative exploration of how caregiver trust is understood and built in CHWs treating their children, using an explicit conceptual framework. This information can be useful support these actors from a program development viewpoint.

Table 2: Articles on trust in CHWs in low-income settings identified in literature

Author/s (year)	Location	Objective	Methodology	Forms of trust	Aspects of trust measured
Ackatia-Armah et al. (2016) <sup>47</sup>	Ghana	Explain how reflective trust was developed as a key influencer in health seeking behaviours.	Ethnographic study with interviews with nursing mothers and focus groups with mothers, health-workers, and community leaders and participant observation	Interpersonal trust in CHWs	Reflective trust in community health nurses
Buchner et al. (2014) <sup>45</sup>	Uganda	Assess whether project stakeholders perceived that iCCM improved access to care for children under five years of age.	Focus groups and key respondent interviews with caregivers, health workers, CHWs and local leaders using semi-structured interview guides.	Interpersonal trust between caregiver and CHW	Trust in CHWs was identified as a theme in the qualitative data.
Elmardi et al. (2009) <sup>48</sup>	Sudan	Feasibility and acceptability of a home based management of malaria using ACT and RDTs	Pre and post-intervention assessments using household surveys, focus groups with the community leaders, and structured interviews with volunteers, care workers, and record and report analysis.	Interpersonal trust between CHW and patients	Use of RDTs to support the diagnosis of malaria increased community trust in the CHWs

Kok et al. (2016) <sup>49</sup>	Ethiopia, Kenya, Malawi, Moambique	Exploring the relationships between CHWs, communities and the health sector.	Qualitative comparative study	Interpersonal trust between CHWs and patients, and CHWs and the health sector	Factors influencing levels of trust include organizational support, feedback mechanisms and reward systems. The dimension of loyalty, familiarity, fairness and recognition were found important to CHWs' relationships with the community.
Mishra (2014) <sup>46</sup>	India	Exploring the experiences of community health workers in integrated service delivery through village level outreach sessions within the National Rural Health Mission approach, implemented in 2005 to revamp India's rural public health system.	Ethnography. Participant observations, open-ended in-depth interviews with 12 health workers, interviews with 8 sub-district level health officers, and 43 villagers.	Interpersonal trust between CHW and patients	Building relationships with the community is an important trust building mechanism. Social status, modes of communication, ability to cater to community health and non-health needs, and the community's prior experiences with other health interventions and their perceptions of the state.
Muhumuz a et al. (2015) <sup>50</sup>	Uganda	Assess household access, utilization and acceptability of iCCM services in Kabarole District.	A cross sectional household survey with caretakers of children below five years.	Interpersonal trust between CHW and caregivers	Trust in CHWs affects utilization of iCCM services. The study found that caregivers trusted the professional skills of the CHW and their ability to handle their children, leading to satisfaction in services offered under iCCM.

Mukanga et al. (2010) <sup>44</sup>	Uganda	Assess community acceptability of the use of Rapid Diagnostic Tests by Ugandan CHWs, or locally known as community medicine distributors (CMDs)	Focus group discussions with CMDs and caregivers of children under five years, and key informant interviews with health workers and community leaders. Manifest content analysis was used to explore issues of trust in CMDs.	Interpersonal trust between caregivers of children under 5 and CHWs	Trust as a measure of: CMD's commitment to voluntary service, access, and perceived effectiveness of the anti-malarial drugs they provide. Level of education, experience and perceptions about CMD's commitment to work also played a role in trust.
Nanyonjo et al. (2012) <sup>28</sup>	Uganda	Qualitatively explore the acceptability and adoption of iCCM programs.	Content analysis of focus group data and interviews with community members, CHWs, and supervisors in 7 communities.	Interpersonal trust between community health workers and patients	Reciprocated trust between communities and CHWs increased trust. Undesired CHW behavior such as heavy drinking or suspected practicing of witchcraft promoted distrust. Villages that had a policy in place where community members had to visit VHT prior to going to the health center - increasing trust in VHT from the community because the health center had trust in the VHT.
Nanyonjo et al. (2013) <sup>3</sup>	Uganda	To compare caretakers' perceived quality of care for under-5s treated for pneumonia, malaria and diarrhea by CHWs and Primary health facility workers (PHFWs)	Comparative, cross-sectional survey of caretakers of children visiting CHWs and PHFWs for management of malaria, pneumonia and diarrhea.	Interpersonal trust between community health workers and patients	Process measure of Trust as a quality domain; looking at integrity, patience and role of health provider as patient's agent.



Pitt et al. (2012) <sup>51</sup>	Mali and Burkina Faso	Qualitative study to assess community perceptions of and recommendations for intermittent preventive treatment of malaria in children (IPTc).	In-depth individual interviews and focus group discussions with caregivers and CHWs.	Interpersonal trust between CHW and patients	Social norms and structures in the countries encouraged trust in and respect for health staff (including CHWs).
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## Chapter 3: Conceptual framework

The conceptual framework for examining trust in this study is derived primarily from Hall et al.'s (2001) conceptual models of dimensions of trust with some reference to Gopichandran and Chetlapalli's (2013) conceptual model for resource poor settings.<sup>36,52</sup> Hall et al.'s conceptual model was derived from common dimensions of trust found in the literature of trust in medicine and more broadly in resource rich contexts.<sup>36</sup> Hall et al identified five dimensions of trust in their conceptual framework: fidelity or loyalty, competence, honesty, confidentiality, and global trust.<sup>36</sup> Gopichandran and Chetlapalli's study in India which consisted of interviews with migrant construction workers in a metropolitan city, and residents of a rural area with poor health indicators came up with the dimensions of loyalty, competence, treatment assurance, willingness to accept drawbacks of the doctor / facility, and respect.<sup>52</sup>

In their paper, Gopichandran and Chetlapalli argue that the dimensions of confidentiality and global trust are not as relevant in resource poor health-care settings.<sup>52</sup> This is because they felt that in rural, resource poor settings where access to health care is limited, getting appropriate care takes priority over concerns about whether medical records are being kept confidential. In the Ugandan context, the subject matter (child malaria, diarrhea and pneumonia) is not sensitive in nature, which I believe makes confidentiality even less relevant as an important dimension of trust in the iCCM CHW. The authors did not find honesty to emerge as an important dimension of trust in their study, but stated that honesty was associated with honest economic exchanges rather than disclosures of mistakes.<sup>52</sup> The other dimension, global trust, is defined by Hall et al. (2001) as a catchall term for all that cannot be categorized into the other dimensions of trust. They define global trust to represent a "component that is irreducible or not subject to dissection

– what one might call the “soul of trust”.<sup>36</sup> For the purpose of this study, I considered global trust to be a vague concept that would be difficult to explore in a cross-cultural study and so did not include this as a main dimension of trust.

I chose to base my framework closer to Hall et al.’s model because it was constructed from multiple findings in the literature and is broader in scope, which is better suited for an exploratory study. While Gopichandran and Chetlapalli’s study aim was to explore dimensions of trust in resource poor settings to contrast Hall et al.’s model, I did not include their dimensions from their model as they were strongly influenced by the specific study context, particularly issues around patients paying for services. In addition, and more importantly, the authors were inconsistent in how they defined and supported their versions of dimensions of trust. For example, some dimensions were supported by the patient’s actions (e.g. the dimension of respect was supported by patients showing respect to the doctor), and other dimensions were described how Hall et al defines them, where the focus is on the actions and characteristic of the provider (e.g. perceived doctor competence). In the end, I chose to explore the trust caregivers have in the CHW utilizing Hall et al’s dimensions and their definitions, though considered omitting or revising some dimensions based on findings from Gopichandran and Chetlapalli.

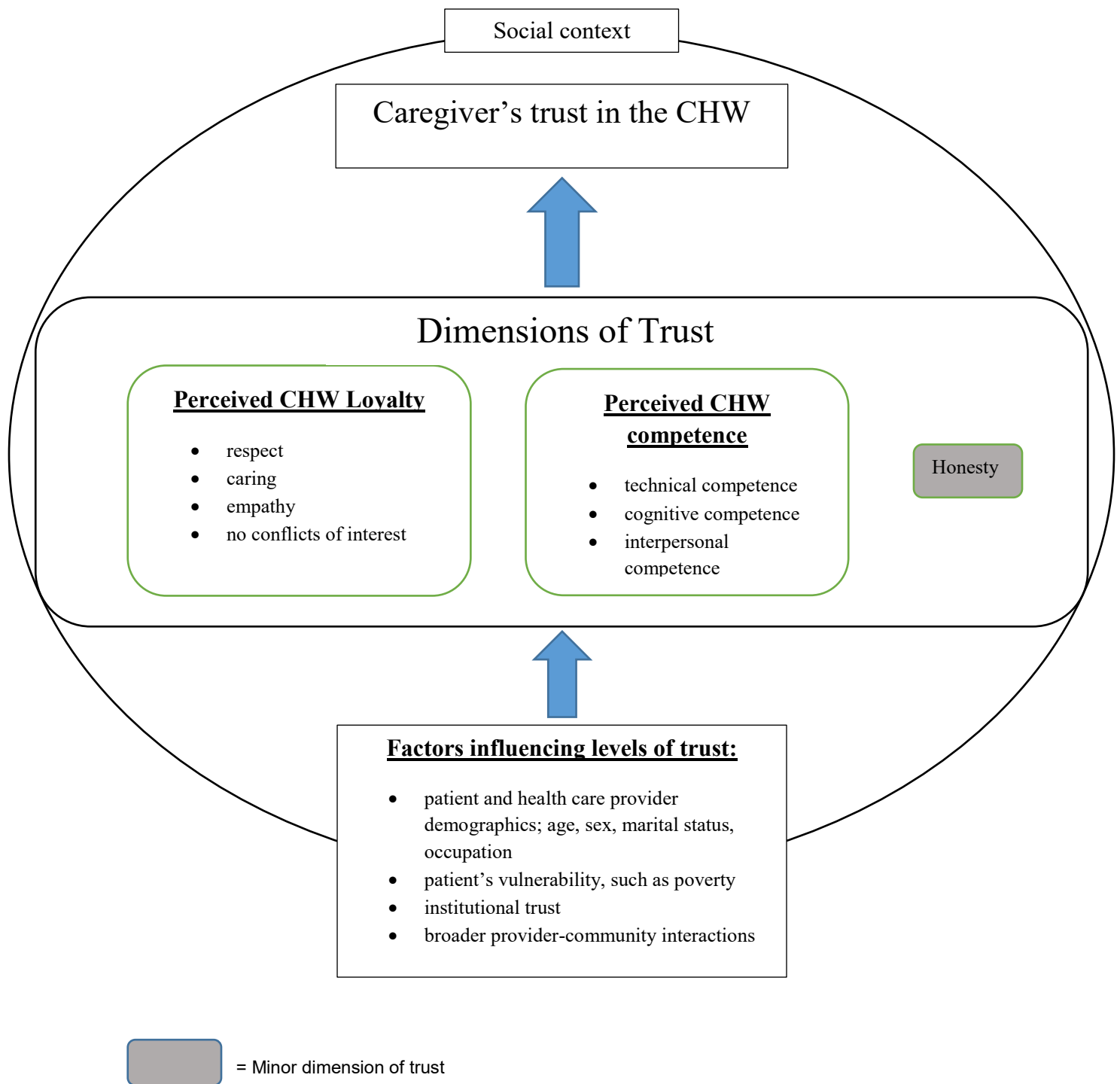
In selecting the final conceptual model for my study, I went on the premise that the two main dimensions of trust that are most relevant to a CHW-based health system in rural Uganda are a caregiver’s perception of CHW loyalty and competence. I explored honesty, but listed it as a minor dimension in my conceptual framework based on Gopichandran and Chetlapalli’s findings where honesty was not a main dimension in their study. Loyalty is a broad dimension that means having an impartial concern for the patient’s well-being, which can be demonstrated by being caring, respectful, being empathetic and avoiding conflicts of interest; all of which are

linked to interpersonal trust.<sup>36,37</sup> Health worker respect for the patient is vital for a patient to trust, and is important because it reflects directly on perceived health worker motivation.<sup>36,53</sup> Respectful care includes being treated fairly, and can be influenced by broader, institutional factors, such as the health system's capacity for the providers to work effectively, and remuneration.<sup>4,53,54</sup>

The second dimension, competence, refers to avoiding mistakes, either cognitive (meaning errors in judgement) or technical, and producing best possible health outcomes. Cognitive competence is most likely appraised by lay people by how an individual handles everyday situations; (does he or she generally make good decisions?) rather than competence in terms of medical judgement, by someone who is not medically trained. Likewise, technical skills are not often easily assessed by someone who is not medically trained, and it is likely that patients also assess competence through proxies such as interpersonal and communication skills.<sup>36</sup> In resource poor settings, judgements about competence by laypeople was found to be related more to perceptions of a correct diagnosis and observations of professional services such as lab tests and giving appropriate medications instead of stating instances of medical errors and best possible care.<sup>52</sup>

Other factors that may influence levels of trust, based on the literature, are included in my conceptual model, and include patient and health care provider demographics, the patient's vulnerability, or broader community-CHW interactions which may influence personal opinions and institutional trust.<sup>36</sup> Figure 1 provides a diagrammatic summary of the conceptual framework I used.

Figure 1: Conceptual framework for examining trust in this study



## **Chapter 4: Research question**

What trust do primary caregivers of children under five years old have in CHWs who provide iCCM care in Kyenjojo, Uganda, and what influences their trust in the CHWs?

### **4.1 General objective**

This research aims to generate knowledge about select dimensions of trust between the community and iCCM CHWs in rural Uganda and the factors that influence this trust. The findings can inform iCCM program managers and policy, resulting in more effective CHW-based services and better child health outcomes

### **4.2 Specific objective**

This research aims to generate knowledge about the trust primary caregivers of children under 5 years have in CHWs to diagnose and treat children under the iCCM strategy through an understanding of perceived loyalty and competence and will examine the effects that different factors have on this trust.

## Chapter 5: Methods

### 5.1 Study design

This study was conducted using a qualitative descriptive approach, grounded in a cross-cultural context in which my culture as a researcher was different from the participants in the study. The qualitative descriptive method is considered an appropriate approach where a comprehensive description of the phenomenon is desired.<sup>55</sup> The qualitative description approach does not require high levels of abstraction, and the researcher stays close to the data to produce the summary and description of events.<sup>56</sup> Qualitative descriptive studies can take on “overtones” of other qualitative methods, and this study incorporated aspects of focused ethnography. Ethnography is the study of a culture or a specific social setting with the end result being an attempt to describe the culture from the point of view of the individuals in the group.<sup>56</sup> In comparison, focused ethnography is the study of a particular aspect of a culture or community, guided by a specific research question backed by background knowledge with the aim to inform decision making regarding a specific problem.<sup>56,57</sup> According to Mayan “compared to traditional ethnography, (focused ethnography) is more time limited. Participant observation is often conducted at particular times or events, or not at all”<sup>56</sup> and involves a limited number of participants who usually hold in-depth knowledge of the topic.<sup>57</sup> Because a true ethnographic approach warrants significant time and resources outside the scope of a Masters project, aspects of focused ethnography were incorporated to inform the research question as a practical and suitable alternative.

## **5.2 Context**

Much of the information of the study setting has been adopted from the 2009 Kyenjojo District Statistical Abstract <sup>58</sup> and my own personal field notes.

This study was conducted in Kyenjojo district of Uganda from September to December 2015. In 2010, a consortium of local and international partners working with the Uganda Ministry of Health established a pilot iCCM program in the Kyenjojo district using VHT members to support community level diagnosis and treatment of fevers in children under five years of age.<sup>12</sup>

### **5.2.1 District study location and population demographics**

Kyenjojo District was created in 2000 out of a larger district (Kabarole), and is made up of two counties (Mwenge and Kyaka) which share 13 sub-counties, 71 parishes, and 701 official villages. The study sites are located in Mwenge County, in Bugaaki sub-county, which consists of 5 parishes and 56 villages. The District has a total land area of about 4,059 square kilometres, and is endowed with national parks, game reserves, forests, and alpine hills. The Mpanga and Muzizi rivers run through and forms borders to the neighbouring Kabarole and Kibale Districts. Kyenjojo District is composed of many tribes, mainly from western Uganda. The majority of the population are Batooro, and the main dialect spoken is Rutooro.

In 2012 the estimated district population was around 549,000, with 58% of the population under 18 years of age. This age structure has consequences on individual incomes because of the resulting high levels of dependency.



### **5.2.2 District health infrastructure**

There are three health sub-districts in Kyenjojo District; Kyenjojo in Mwenge South, Kyarusenzi in Mwenge North, and Kyaka in Kyata county. Each health sub-district has a District Health Centre IV, where the highest cadre of staff is a doctor. At the lower health centre levels (II and III), the health units are staffed by clinical officers or other staff such as nurses. Based on 2009 data, Kyenjojo District has 27 health centre II and IIIs, and 12 private and private not for profit clinics. The district ratio of medical practitioner to population is worse than the substandard national average; in Kyenjojo there is 1 doctor per 111,250 compared to the national estimate of 1 per 24,725.

Kyenjojo District has poor access to health services for both urban and rural populations, compared to the national average. The Uganda Ministry of Health deems having physical access to a health facility as living within 5 km of a health facility,<sup>16</sup> while over 45% of rural households in Kyenjojo access health facilities that are more than 5 km away.

## **5.3 Study population**

The study population was primary caregivers (parents, grandparents or guardians) of children under five years old living in two selected villages in the Kyenjojo District, Uganda. Two sites at different distances from the nearest HCIII were selected for the study because the degree of trust in CHWs may depend on the proximity of the nearest health clinic. We randomly selected 28 caregivers who were 18 years old or older, and who had previously brought their sick child to the iCCM CHW for care within two years of the start of data collection in September

2015. We identified these caregivers by looking through the CHW's patient log book, which has information about each child they attended to and the date of the visit. The choice of a two-year timeframe from the start of data collection was to ensure that experiences would be based on a point when the iCCM program would have been well established.

## **5.4 Sampling procedure**

The two villages in Kyenjojo District were selected with the guidance of the Kyenjojo Health Department. The health department helped identify appropriate villages that are currently active in iCCM programs and that are logistically suitable to work in. We chose villages that were accessible by public transportation (bus and motorcycle taxi) to stay within budget. The District Health Officer (DHO), the Deputy DHO and the iCCM focal person for the District provided essential insight on the local road conditions to potential villages. Some villages were not easily accessible by local motorcycle transportation during certain times of day based on local motorcycle driver availability. Others required a personal vehicle to access them. Such villages were eliminated for feasibility reasons.

Since the Uganda MoH deems being within 5 km of a health facility as having physical access to it, the Kyenjojo Health Department helped identify a village that was 3 km from a government health facility (HC III) and one that was just over 5 km as study sites. This was to see if the responses from the caregivers differed depending on their proximity to the nearest government health facility. From speaking with both CHWs in each village, one was estimated to have approximately 80 homes with 35 children, and the other much larger at 135 homes with 100

children. In addition, the DHO was knowledgeable about village demographics and ensured that the villages selected represented typical villages for the District.

Letters of introduction to present to the village leaders were provided by the DHO. The District Health Inspector introduced the study team (me and two research assistants) to the two iCCM CHWs working in each village. All four CHWs were middle-aged mothers. The CHWs provided the study team with their iCCM rosters of children in the village who visited them for medical care. The CHWs also provided a list from memory of the children that had visited them, but were not documented in the roster because the CHW had no drugs to dispense to the caregiver. From these lists, I randomly selected seven children from each CHW's roster (14 children per village) by writing each name on a piece of paper, thoroughly mixing the pieces of paper in a bowl, and having a staff member at my place of residence pick seven names per CHW (two CHWs per village). With the help of the CHWs, the caregivers of the children selected from the records were identified. We arranged appointments with these caregivers with the help of the CHWs; ideally, two participants per field day. Since homes in the villages were often hard to locate because of reasons such as long distances from the main roads on unmarked paths, it was necessary that we were escorted by the CHWs.

Participants not available for interviews were replaced from the remaining names using the same process as described above. This occurred three times; once a caregiver was absent from the village. The second time, the husband did not allow his wife to participate because he was not consulted prior to our arrival. The third time, a caregiver was not at home.

## **5.5 Data collection**

### **5.5.1 Selection and training of research assistants**

Because of the language barrier between me and the villagers, two local research assistants (RAs) were hired and trained to conduct the interviews. These RAs were recommended by my supervisors and a field site coordinator (a colleague of my supervisors), as they had worked as RAs on other research projects. One acted as the interviewer / transcriber / translator and the other RA was the note-taker for the study. A third RA assisted with transcribing and translating the interviews into English when the work load was too great for the interviewer. All three RAs had college educations and were fluent in both English and the local dialect, Rutooro. They knew each other from previous work engagements, and all had a good working relationship with one another. To ensure that the transcriptions and translations were valid, the two transcribers were asked to transcribe and translate the same sections of two interviews, and the English transcripts were cross-referenced with each other. Cross-referencing was done once prior to data collection using pre-test interview recordings, and once again in the middle of the data collection period to ensure the translators were consistent in their translations. The review occurred in a meeting with all the RAs and the text was discussed as a team. I found very minor discrepancies between the two transcripts during review and no major differences in interpretation or use of English words.

I worked closely with the RAs, the field site coordinator, and other community members fluent in both Rutooro and English to ensure the interview topic guide conveyed the concept of trust as accurately as possible. Based on early interviews, the topic guide and instructions to the research assistants were modified to ensure that the interviews were better connected to the

research questions. Modifications to the topic guide were made continuously throughout the data generation period.

### **5.5.2 Development and pre-testing of the topic guides**

Before the formal interviews, an informal group discussion with eight caregivers was facilitated by the research assistants. These caregivers were selected by the Kyenjojo Health Inspector from a village with the same population characteristics as the two selected study villages. We used this opportunity to better understand how trust is spoken about and understood in the local context. We explored how trust is expressed, what are indicators of care and respect to them, how they view CHW competence and what were their expectations of CHW competence. This conversation also provided an opportunity to ask and learn about the different beliefs in the community, for example, towards health care. Information gathered from the group discussion helped inform what words to use and how to phrase questions in the interview topic guide.

Once the final interview topic guide was completed, it was pre-tested using two caregivers from the same village as the members of the informal group discussion. Pre-testing was done to ensure that the translations of the questions were appropriate, and that the questions were eliciting the desired conversations. Adjustments to the questions and probing questions were made accordingly. The results of the informal discussion, pre-testing, and multiple lengthy discussions with the RAs, project manager, and other informants in Fort Portal were important for the fine-tuning of the interview topic guide to ensure the use of correct terminology and that it was as culturally appropriate as possible.

### 5.5.3 Interview procedure

Over the course of September to December 2015, two rounds of semi-structured interviews with open-ended questions were conducted with each participant except for one who was away from the village during the second round of interviews. The interviews were conducted in a private setting at the participant's preference for their convenience and comfort. Most interviews occurred either inside or near the home. Tokens of appreciation were given to the caregivers at the completion of the interview. These were not mentioned prior to the interview to prevent any biased participation. After the first interview, caregivers were given a large bar of laundry soap, and after the second interview, they were given a 1 kg bag of sugar. The soap and sugar were recommended by the RAs and those with previous experience in research in this region as appropriate tokens of appreciation for the villagers.

The first interview was broader in nature, guided by the topic guide (see Appendix I) while the second interview was used to seek clarification from the participant if needed, and to probe further into findings from the first interview. The timing of the second interviews varied by participant, and ranged from 2 weeks to one month after the first interview. The data were reviewed iteratively and ongoing changes were made to the interview guide over the course of data generation.

During each interview, two RAs were present; one interviewer and one note-taker, and the interviews were audio-recorded. Out of a total of fifty-five interviews, I was present for twenty-one. I chose to opt out of field visits because I was concerned my presence made some participants uncomfortable. All interviews were conducted by the same RA in Rutooro, the local dialect. The role of the note-taker was to capture the general impression of the interview, as well

as important contextual information in English. In addition, if I was present during the interview, the notes enabled me to follow along in real time and ask questions when required. Because these notes provided contextual information on what happened during the interview, they were available to refresh the RA's memory during transcription since we often interviewed more than one caregiver per day.

English-translated transcripts were produced as soon as possible by the interviewer, or the third RA who was experienced in transcribing and translating interviews. The RAs listened to the Rutooro interviews and transcribed them directly into English. The field days were spaced out to allow time for the RAs to transcribe and translate the interviews into English for me to review. The spacing of interview days allowed the interviewer, note-taker, and me to discuss the initial findings and procedures. The immediate review of interview transcripts allowed for timely changes or refinements to the questions and interviewer approach prior to conducting additional interviews in order to generate the richest data possible. This was an important and useful process, especially during the beginning of the data collection. Having planned two interviews per participant gave me the opportunity to ask caregivers to elaborate or clarify anything that was not clear in the first interview if necessary. It was our hope that repeat contact would help build rapport between the study team and the participant, and that the participant would be more comfortable during the second interview, which seemed to be the case.

## **5.6 Overview of data analysis**

Data analysis occurred in iterative stages throughout the data collection, in which data were collected and analyzed, then more data were collected to fill in gaps, analyzed, and so on.

The data were analyzed using content analysis, which is the most appropriate analytic technique for descriptive qualitative and/or focused ethnography studies.<sup>56</sup> More specifically, latent content analysis was used in which primary patterns in the data are identified, coded and categorized and where the researcher codes “participants’ intent within context”.<sup>56</sup>

On average, the RAs required two days after receiving an interview recording to transcribe and translate an interview. After each day of fieldwork, the note-taker gave me the interview notes for review. These were especially useful when I did not go to the field, as it allowed me to get a general idea of the interviews while I waited for the transcripts. The majority of the transcripts given to me by the RAs were hand written. I would first read over the hand-written transcripts once and make comments or highlight sections of anything that was striking, or that I should return to. If I had any questions about the data, or issues to discuss with the interviewer about probing questions or wording, I would mark the transcript for discussion with the team prior to the next field day. After reading the hard copy, I would then type the transcripts into Microsoft Word and assign line numbers to each paragraph for ease of reference. I made comments on the electronic copy during subsequent readings. Each participant was assigned a unique case letter or number to identify which village they were from. Participants from the near village were given number prefixes, while participants from the far village were given letter prefixes. These identifiers were used to correspond the RA interview notes to the transcriptions. All data were maintained through a combination of electronic and hard copy versions.

Re-reading of the interviews and coding occurred throughout the data collection process. Emerging themes helped guide the direction for probes or future questions in interview two.



A database of the transcribed interviews and observation notes was created in NVivo 11 software to further aid in the management, coding and analysis of data. Going through the data again, a list of codes was created that were then organized into categories. Because content analysis is a cyclical process, the categories and subcategories shifted and changed over time as new ideas emerged. The conceptual framework for examining trust provided a basis for initial coding of the data. Categories were created keeping in mind internal homogeneity criteria, where all the data reflect the category, and external homogeneity criteria where the relationships among the categories are distinct and separate.<sup>56</sup>

## **5.7 Rigor**

Just like quantitative research, qualitative research is assessed for the credibility of its findings. Lincoln and Guba (1985) argued that qualitative research requires a different set of criteria for rigor than the quantitative, positivist paradigm (validity, generalizability, reliability) to which qualitative research is not associated with.<sup>59</sup> In qualitative research, rigor can instead be understood in terms of credibility, transferability, dependability and confirmability.<sup>59</sup>

Credibility refers to the confidence in the ‘truth’ of the findings, and is analogous to internal validity in quantitative research. It assesses whether or not the findings are an accurate representation of the participants or data. Sandelowski (1986) suggested that a study is credible if it describes or interprets human experiences so accurately that people having the same experiences would immediately recognize them.<sup>60</sup> Suggested techniques for establishing credibility include prolonged engagement, triangulation, peer debriefing and member checking.<sup>59</sup>

In this study, a technique to establish credibility was by performing member checks during the second interviews, in addition to the informal community meeting with caregivers and checks with key informants. Participants were given the opportunity to reflect, correct errors or confirm preliminary findings, which could allow for a richer analysis. In addition, the field notes from the RA as well as my personal observational notes were used to compare with the interview transcripts.

Transferability of the findings is analogous to external validity in quantitative research. It refers to the applicability of the findings to other settings, and is acquired by providing a “detailed and thick description of the setting and participants.”<sup>56</sup> Efforts were made to provide a full and accurate understanding of the phenomenon by sampling from two locations and including a variety of perspectives, taking field notes, consulting with key informants and through multiple meetings with the RA team.

Dependability is analogous to reliability in quantitative research, and refers to the ability to review how decisions were made throughout the research process. A technique used to establish dependability was by maintaining an audit trail of my research decisions and activities throughout the research, in personal notes and through emails with my supervisors.

Lastly, confirmability is analogous to objectivity in quantitative research, and refers to the logic of the findings and the extent to which they are shaped by the respondents and not by researcher bias or motivation.<sup>56</sup> Techniques used to establish confirmability was through an audit trail, and reflexivity.<sup>59</sup> I practiced reflexivity throughout the research by keeping a personal journal in addition to memoing throughout the data analysis. I scheduled reflexive discussions with the RAs throughout data collection to better understand how their perspectives have shaped

the data, and to make sure we were on the same page on key concepts and terms and goals. To ensure the interviews are all being transcribed appropriately, sections of the transcripts from both transcribers were compared against each other. I was aware of the role I may have played in shaping the data when I was present during the interviews. As a Chinese-Canadian woman, my visible differences may have affected how the participants viewed the research, or how they decided to respond to the questions since I am an “outsider” to the community. On the other hand, I may have been perceived as an “insider” with women participants that I encountered because I am also a woman.

The RAs who were conducting the interviews were locals from the neighbouring district and spoke the local dialect fluently. The interviewer was a female in her early-thirties, while the note-taker was a male in his mid-twenties. Both were experienced in field-work in villages, and seemed very comfortable visiting homes and interacting with the CHWs and the village caregivers. The female interviewer was the main point of contact between the CHWs and our study team, as well as the main interactor with the caregivers. The note-taker played more of a “back-seat” observer role during the interviews, sometimes asking questions at the end of the interview for clarification. Although the RAs are both Ugandan and locals of a nearby district to the study sites, it is possible that caregivers felt intimidated because the RAs were educated, and / or doing formal research. Over the course of data collection, I had several conversations with the RAs. They believed the caregivers were comfortable in their presence, and were being honest during the interviews. However, it is not possible to say definitively that all participants felt that way.

## **5.8 Ethical Considerations**

This research project was reviewed and approved by the University of Alberta, the Makerere University in Uganda, and the Uganda National Council for Science and Technology (UNCST). Permission was obtained from District authorities and local leaders. Informed consent was obtained from all participating participants. Each participant was provided with the informed consent document translated in the local language, Rutooro. Because of the low literacy rate in the villages, the consent form was thoroughly explained in the local language by the trained research assistant. Each participant was then asked to sign or provide a thumbprint on the consent form to indicate their consent to participate.

There were no risks or benefits to the participants for participating in the study. The informed consent clearly outlined the expectations of the study, and we made it clear that the participants could withdraw from the study at any time with no negative consequences. The raw data was kept confidential and the anonymity of participants was maintained. I worked closely with the interviewer so that they were able to accurately answer any questions the participants may have. I made sure the interviewer clearly expressed that no one should feel pressured to participate in the study. Electronic information such as audio recordings and digital transcripts were encrypted and stored on a secured computer.

## **Chapter 6: Findings**

Out of twenty-eight participants recruited from two villages, 26 were females and 2 were males – one from each village. Participants were between 18 and 53 years old, with a median age of 30 years. The number of children ranged from one to eight with a median of three. The

participants' levels of education ranged widely; the majority (17 out of 28 participants) had completed some level of primary school. Seven participants had attended lower secondary school, and four participants reported never attending school. Most of the caregivers were married (16/28), while the rest were unmarried (10/28) or divorced (2/28). Most caregivers were farmers (23/28); one caregiver was a nursery teacher, two owned a small business, and two were housewives.

Content analysis was used to examine themes related to caregiver trust in CHWs. The main themes in this study, guided by the conceptual framework, were a) perceived CHW loyalty, b) perceived CHW competence, and c) factors influencing perceived CHW loyalty and competence, namely; CHW demographics, broader CHW-community interactions, and authority.

Two villages were selected based on their proximity to free-of-charge government run health centre. No difference in attitudes were found among caregivers who lived in the village designated as “close” (3 km) to the free government health centre, compared to caregivers who lived in the village designated as “far” (5 km). In both villages, caregivers mentioned the long distances to walk to the health centre, or the costs associated with hiring a motorcycle taxi.

## **6.1 Caregivers' interpretation of trust**

To understand how local people understood the term trust, during informal discussions which took place prior to the interviews and in the interviews, we asked caregivers what “trusting someone” in general meant to them. We also asked for examples of people they trust, and why.

Confidentiality was a common theme that emerged. Most caregivers spoke about being able to trust a person who would not disclose private information or could keep a secret.

Examples given included nurses who don't reveal personal information such as STIs to anyone else, and friends who they felt could keep secrets.

*"The people I trust are like the nurses, reason being, nurses receive very many patients in a day with several complaints or diseases for example, I may find you coming from her diagnosing room and I enter but she can't tell me what you discussed with her or the disease you are suffering from. Which means she will not disclose my information to any other person after leaving the hospital." (Participant 09; female)*

*"I think trusting someone to me means if you have a problem, you go to that person or someone you can tell your secrets. I will be trusting that person." (Participant 13; female)*

Another reason participants commonly gave for trusting someone was if the individual returned borrowed items or money without any issue.

*"When you trust someone, it means that person doesn't disclose your secrets or when [you] lend something [and they] bring it back peacefully without first quarrelling; that is trusting someone." (Participant 08; female)*

*"Now, trusting someone, it's like, OK, like you as a person we might be here talking or sharing secrets and I don't hear our secrets being discussed somewhere else. There, I would trust that person. In addition, if I have lent you money and you return it the agreed time, I can trust you." (Participant 10; female)*

Lastly, was the importance of a person's character. Caregivers felt that how an individual behaves in the community, how they treat others and whether they act in a responsible manner were important factors for trust.

*"[When] you know that someone is responsible and fulfills their duties, you trust that person." (Participant 02; female)*

*"I can trust someone according to one's conduct and behavior; you can see someone there and you have never had any grudge with them and someone is not a rumor monger, is not a liar and you see someone is just reserved, those are the people that I can trust." (Participant j; female)*

Mannerisms were important. When asked to describe how someone would show respect, the most repeated responses were related to giving a friendly greeting, how they welcomed others into their home, offering a place to sit, and listening to one's concerns.

## **6.2 Dimensions of trust**

Overall, caregiver trust in CHWs was very high. This section focuses on how caregivers perceived this strong trust within the two key dimensions of loyalty and competence.

### **6.2.1 Perceived CHW loyalty**

Perceived CHW loyalty refers to the specific interpersonal relationship between a caregiver and the CHW. When asked about the CHWs, caregivers often spoke about having a positive personal relationship with the CHW and described various interactions as reasons why

they sought care from that individual. This section will explore what the caregivers perceived in relation to loyalty within the following sub-dimensions: respect, honesty and commitment and prioritization of work, which includes empathy. The concept of being a caring person was found throughout all these subdimensions. These sub-dimensions all relate to how caregivers saw CHWs as good people who would be loyal and worthy of loyalty, which then engendered their attitude of trust in the CHW.

#### **6.2.1.1 CHW respect**

Being shown respect was very important to caregivers. Throughout the interviews exploring their trust in CHWs, caregivers described numerous instances of CHWs treating them and their children with respect. CHWs demonstrated respectful care by gestures such as offering a seat to the caregiver and child upon arrival, and showing patience during the visit. Being “warmly welcomed” was frequently mentioned when caregivers were asked to describe visiting the CHW. A caregivers’ first impression of the CHW was clearly important to the caregivers, and being welcomed kindly was an obvious sign of respect and an important factor in developing trust in the CHW. Caregivers saw these as characteristics of someone who is kind, and who makes effort to make others feel comfortable. Such traits are found in people who tend to be well-liked and in general more likely to be trusted.

*“She respected me because she welcomed me inside and she brought me a seat, and we talked very well.” (Participant 11; female)*

*“You put little trust in someone when you go and she doesn’t welcome you” (Participant h; female)*



*“...you really see that she is very kind and loves other people so much; and loves the children that you bring to her.” (Participant 14; male)*

The sincerity of the CHWs’ reception was an important influence on caregivers’ trust, because it made them feel that the CHWs cared about them and their sick children, and that the CHW was a good person:

*“The way she welcomed me showed me that she was caring and she was not like those people who just look at you when you go to their houses... she cared for me a lot...the way she welcomed me made me go back whenever any of my children would fall sick.” (Participant a; female)*

*“Our [CHW] treated me with respect, she gave me a very good reception which showed that she was a good person.” (Participant 11; female)*

This was in sharp contrast with the caregivers’ experiences with nurses and other medical staff at government health centres. Many complained about poor staff attitudes and treatment at such facilities, and especially about nurses who they felt were unfriendly, unwelcoming and often seemed annoyed at the caregivers.

*“We... go to the government hospitals and the nurses just look at us and abuse us because [they are] annoyed, and sometimes we leave the hospitals with our sick children unattended to” (Participant 09; female)*

*“When I entered her [the CHW’s] house, she welcomed me and asked me the reason why I had brought the child at such an hour in the night. I explained to her the problem and she reassured me that the child will be OK. I felt relieved as she has not barked at me but respected me. Because you can go to other hospitals and someone says “you please wait, you go there.” But our CHWs don’t do such things, both of them.” (Participant c;*

*female)*

Caregivers often mentioned their experiences of not receiving impertinent comments or feeling looked down upon when visiting the CHW to seek care. Caregivers felt good when CHWs welcomed them with a good attitude rather than getting reprimanded for their child's illness state. Being treated well by the CHWs influenced their trust in them.

*"[CHWs] don't scold us... Each time you visit them, their attitude is good, they treat us well." (Participant 02; female)*

*"... the [ CHW] welcome[s] everybody irrespective of how they look, and...all people no matter where they come from" (Participant 12; female)*

*"If I go [to the clinic] with a sick child and [health workers] scold me, there I trust them less because they scolded me, yet I had a sick child." (Participant 1; male)*

When asked a hypothetical question about whether they would seek care from a CHW who had not treated them with respect, most caregivers said they would seek care elsewhere regardless of the quality of medical care. In the caregivers' eyes, disrespect from the health provider was a sign that the health provider may not have their best interests at heart and made caregivers wary of the quality of care received in their hands.

*"Someone barking at you when you have taken your child for treatment? I would definitely not go back. I would not go back there and I would even fear to give her my child to treat her. I cannot give her my child. Because she has barked at me and treated me badly" (Participant 14; male)*

*"If someone shouts at you, you fear going to them. They abuse you, shouting "why did you delay bringing the child for treatment?" Even when you visit big hospitals and health*

*workers abuse you, you fear going back and decide to seek care somewhere else.”*  
(Participant 11; female)

However, two caregivers did disclose that hypothetically, even if the CHW was rude and disrespectful, they would still go to the CHW if the medical treatment was good - primarily for the sake of their child's health. This may point to their strong trust in the CHWs' competence to effectively treat their children, which will be discussed in section 6.2.2.

Another trait related to respect was patience and taking time to explain things. Caregivers frequently mentioned that the CHWs were patient with them, and explained diagnostic procedures and how to administer medication to the child. Caregivers appreciated the explanations of procedures and felt that this showed respect for them and their children, and which led caregivers to trust these CHWs.

*“we put our trust in her because she explained everything to us”* (Participant b; female)

*“...when you go there she first explains to you what she going to do to your child. She tells you that she is going to bleed the child and she will put blood in her machine [RDT]. She describes to you that if you see anything changing like this or like that, that would mean that the child is negative or if you notice any change then that means the child is positive. Then when she puts the blood in the machine [RDT] and you compare with what she has told you, you also know that the child is sick. That is [why I] trust that CHW.”*  
(Participant a; female)

### 6.2.1.2 CHW honesty

Another feature mentioned by caregivers was the honesty of the CHWs. Compared to the other subdimensions, honesty was not as strongly mentioned by the caregivers and came up most often in the context of drug shortages, which happen frequently and was the current situation at the time of the interviews. In instances where the CHWs claimed to not have any drugs in stock, caregivers did not feel they had to question the CHWs on what happened to the drugs.

Caregivers seemed to trust that their CHWs were telling the truth and were not stealing the drugs for resale and personal profit, which was said to happen in other locations.

*“She cannot lie to you that the drugs are out of stock when she has the drugs. She tells you the truth that she doesn’t have drugs.” (Participant i; female)*

*“In other villages, people were complaining that the [CHWs] were selling drugs, but I have never heard it being said about our [CHWs]. To be sincere, our [CHWs] have been good to us. They’re trustworthy.” (Participant l; male)*

Some caregivers mentioned private health clinics as providers they felt were not honest. Caregivers believed staff in these private fee-based clinics were dishonest and only there to make a profit. This sentiment was not expressed towards government run health centres, which suggests a trust that government programs would not take advantage of the people, perhaps because there would be no financial gain in giving an incorrect diagnosis. The influence the government and other authority figures have on caregiver trust is explored later in the thesis, in section 6.3.

*“I don’t trust private clinics that much, because they are after making money...Every time you go there, they always give positive results. It’s a sure deal they want money. They test the child, give positive results even when the child doesn’t have malaria due to*

*their love for money.” (Participant 10; female)*

Another area where caregivers felt the CHWs were honest about was the extent of their capacity to treat. Caregivers stated multiple instances where the CHW would refer them to higher facilities where trained medical staff could better treat their child. This honesty reassured caregivers that the CHWs stayed within their scope of care, and that their child’s health was their number one priority, rather than personal ego.

*“I felt okay, was I not with the Doctor? <laughs> Sometimes she tells you if she is unable to manage your child and she refers you the Doctor in other health centres.” (Participant 04; female, close)*

*“Before I decide to go to the hospital, I first visit the [CHW], if she can’t afford [to treat] the child, she’s the one to do what? To refer me to [the government health centre].” (Participant 10; female)*

#### **6.2.1.3 CHWs showed commitment and gave priority to their work**

Caregivers felt that CHWs prioritized children’s care over their own interests. Caregivers spoke about how they felt that CHWs demonstrated great concern for their child’s health and that they consistently helped them and their children to the best of their abilities. Many gave anecdotes of instances where they felt the CHWs took the health of the child seriously and went out of their way, and beyond what others would do to assist them as reasons for why they trust the CHW and return to the CHW for their child’s care.

*“You can’t doubt her capability...she’s someone who is hardworking and intelligent. You at least know she will try her best to treat the child.” (Participant 13; female)*

*“When you are in need, she has a heart of helping us. She makes sure that she fulfills her duties, especially when drugs are out of stock. She looks for a way of helping us.”*

*(Participant 02; female)*

*“She helped me and carried my child who was very sick... she escorted me and I boarded a boda-boda (motorcycle taxi) to [the health centre]. Another person cannot [would not] do this... But for her, she even escorted me and according to how she assisted me, I have trust in her.” (Participant 08\_01; female, close)*

Caregivers also reported the CHWs would attend to them in a timely way, no matter what they were doing when the caregiver visited their home. Caregivers stated they usually found the CHWs in their gardens farming, performing other housework such as cooking, or even sleeping, but they all said that the CHWs would stop to assist their sick child. Some even said the “CHW came running” to describe the sense of urgency in which the CHW would attend to them.

*“I found her cooking and as soon as she saw me, she stopped, washed her hands very well and started treating my child, to show how caring she was. But when you visit other people and find them cooking they say that “first wait while I finish cooking, then I’ll come to attend to you.” She didn’t show that to me.” (Participant 05; female)*

Another caregiver said:

*“...when you go to her home with a sick child, she quickly moves from the garden, washes her hands and treats the child there and then. When she’s eating or cooking, she has to first leave what she’s doing to attend to your child.” (Participant 02; female)*

Multiple caregivers mentioned the CHW’s commitment and passion towards the job, shown in part by seeing the CHW actively at work even though this was not their primary job.

*“I trust her because I even see her checking on pregnant women in our village and she writes down their names...I felt very happy because she came and explained to me how I can get help in case there is any problem... you cannot say that the person is bad because... she is fighting for your life.” (Participant g; female)*

The commitment of CHW to their work may be related to how they were perceived to empathize with the caregiver. This may be due to shared experiences and demographics between caregivers and CHWs. In both villages, the CHWs were mothers, and a sentiment among the caregivers was that since the CHWs had children of their own, they knew what it was like to have a sick child. Most participants felt women who had children were more suitable for the position as iCCM CHW, because they would have had similar experiences and the resulting ability to empathize with a worried parent.

*“She knows what a mother goes through when her child is sick. She just imagines how someone feels when their children are sick and she shows empathy.” (Participant 03; female)*

*“To be sincere, I never had any doubts. When I reached her home, I saw that she was concerned as a parent. It’s good she’s a parent too. I didn’t doubt, I thought she was going to help me.” (Participant l; male)*

This view was also expressed by the same male caregiver:

*“Women were created differently by God. They are empathetic in their own way. Women are so merciful.”*

*Interviewer: How about men?*

*“We too feel sorry for people but women play a big role in children.” (Participant l; male)*

In contrast, some respondents felt that some nurses at the health centre may be rude or condescending because they did not have the experience to relate to their hardships, such as village life, or being a mother. Some did not feel that the nurses at the government health centres empathized with their situation, which hinders the formation of a trusting relationship.

*“They don’t know the pain of mothers when their children fall sick. You can even take a child to the hospital without washing and the nurses just laugh at you; those young girls who have not yet produced any child.” (Participant i; female)*

### **6.2.2 Perceived CHW competence**

Perceived CHW competence and skills also emerged as an important dimension of trust. This section explores what caregivers saw in relation to CHW competence, and what caregivers determined as important markers of CHW competence. In their interviews, caregivers highlighted the following sub-dimensions of competence: 1) CHW interpersonal skills; 2) technical skills which were represented by diagnostic capabilities and child recovery; and 3) cognitive skills which were represented by effective medical and child health advice. In many instances, caregivers’ perceptions of CHWs’ competence were intertwined with their perception of caregiver loyalty. In this section, efforts were made to separate out those characteristics related to skills and competence that would have led to positive actions and behaviours

While this study asked caregivers about their knowledge of CHW training, many believed that they were trained, but did not know specifics about the training. Rather, they focused on the above sub-dimensions of competence, such as CHWs providing good diagnoses



and their child recovering, as evidence that they were trained.

#### **6.1.2.1 Interpersonal skills**

Throughout the interviews, caregivers noted the CHWs' good interpersonal skills, including communication skills and their approach toward the child and caregiver. Caregivers also mentioned the CHWs' abilities to interact with children which in turn influenced how they perceived other CHW attributes, such as being a caring health provider, and having theirs and their children's best interests at heart. Interpersonal skills are the underlying foundation for many characteristics addressed in the dimension of perceived CHW loyalty (section 6.2.1). Many of the caregivers' reflections on respectful and empathetic behaviours that contribute to perceived CHW loyalty involve good communication skills.

*“She talks so well to children. You see her, asking the child how s/he is feeling, she holds the child very well. In other words, she bonds with the child so well. That is what I know about that woman. She also makes you sit comfortably in her house. She can't ignore you or leave you outside and she goes inside to get drugs. No, she tells you to go inside while there, she makes you comfortable then [you] explain the child's condition to the [CHW]”*  
(Participant j; female)

One caregiver provided advice for future iCCM CHWs, in which he stressed the importance of the CHW's relationship to children and the community in gaining trust in the CHW:

*“If I were to advise someone how a good CHW should be like, I would say that a good CHW should be loving children, should love many people, and more so the village mates so that they put more trust in her in order to seek treatment from her.”* (Participant 14;

male)

### 6.1.2.2 Technical competence

Technical competence refers to the performance of the CHW in regards to the examination of the child, consultations and other procedures, and may be hard for caregivers with no medical background to assess. In this study, caregivers tended to connect CHW testing and diagnosis and the child's recovery as evidence of the CHWs' technical skills. In some situations, caregivers pulled from their experiences at health centres to inform their perceptions of CHW technical skills.

### Diagnostic and treatment skills

Caregivers expressed great trust in the CHW's ability to treat their children. They built their trust in the CHW because they would first test and then diagnose a child's illnesses prior to giving drugs. Receiving a diagnosis based on a test, be it a blood test or an examination of the child's symptoms was frequently mentioned as a reason for bringing their children to the CHW.

*"[Drug shops] give you drugs before testing you first. They don't test your blood but they sell the drugs to you as you have gone. But these others they first test your blood and give you drugs after knowing what to do." (Participant h; female)*

*"When I go there there's [testing equipment] she uses to first diagnose my child then tells me what the child is suffering from. When I go to her, I go there...with a lot of trust and happiness knowing that... I will know what disease my child is suffering from." (Participant e; female)*

*“There are some people who just give treatment to children without observing the child’s condition and the end result is always bad.” (Participant 1; male)*

Caregivers noted the similarities of services between the CHWs and formally trained health providers. A commonly given reason for visiting the CHW for care was that the services seemed to be comparable to that at the clinic or health centre. Almost every caregiver we interviewed said they would go to the CHW first before the clinic or health centre for this reason. As a result, this suggests that they viewed the technical skills of the CHWs as equal to those of nurses.

*“...I can’t think of going to the clinic because they offer similar services. Besides, many people usually visit private clinics for blood testing services but if the [CHWs] are doing the same why should I go to private clinics yet the [CHWs] do it too? (Participant e; female)*

*“What would you be looking for in the clinic? You just go to the CHW and she treats the child and the child becomes OK. Even if you go to the clinic they will treat your child and he becomes OK [so] then why not take the child to [the CHW].” (Participant 07; female)*

More specifically, caregivers saw similarities in the process used by formal health care workers and CHWs. Examples caregivers gave of CHW ‘testing’ ranged from pricking the finger for a RDT for malaria, testing the child’s temperature, to listening to the child’s breathing. A diagnosis based on tests similar to what they saw at a clinic, hospital or health care centre gave caregivers peace of mind knowing what disease their child is suffering from and showed CHW competence.

*“...she really tested the child’s blood... and that was very important. At first I was surprised, I thought blood testing was only done in hospitals yet the [CHWs] also test.”*

*(Participant 1; male)*

Caregivers even saw the CHWs as similarly skilled as nurses, which indicates their confidence in the CHWs' abilities. When asked if she would have rather gone directly to a health centre, even if money was not an issue, one caregiver responded:

*“No, because I [have] trust in [the CHW] and I take the child with fever and I explain to her. She checks my child and finds the fever and she gives me the drugs and the child completes the dose and becomes ok. Why should I go to the hospital when we have our nurse nearby?” (Participant n; female)*

Caregivers didn't just see the similarity in physical tests, but also the similarity in communications and interactions. Many caregivers mentioned that the CHWs would ask questions similar to what a nurse would during each visit. Caregivers interpreted the CHWs' basic medical questioning as a sign the CHW had the competence to be doing the job.

*“...Because if she was not knowledgeable she wouldn't have asked all those questions about the child. That is why I developed trust in the [CHWs] and I knew that they know what they are doing and I accepted to take there my children to receive treatment.” (Participant 14; male)*

However, it is important to note that the caregivers' trust in the CHWs was not a blind trust. They stated knowing the difference between the CHWs or “village-nurses”, and formally trained nurses at the health centres and clinics. They exhibited awareness of the limitations of the CHW's treating abilities, and knew that some illnesses required medical attention beyond the CHW's scope. Caregivers were comfortable with what was currently provided, yet they

expressed that they would feel nervous if the CHW started offering injections or IVs, which was recognized as a skill requiring advanced training:

*“Even when I have money, I have to first take the child to the CHW, that is if the child isn’t badly off and the CHW can give treatment with the drugs she has. In other words, if there’s no need of giving IV fluids (drip). When the treatment given by the CHW doesn’t help my child, I go to another hospital the following day.” (Participant j; female)*

Though the majority of caregivers stated going to the health centre as a last resort after seeking care from the CHW, two caregivers out of the twenty-eight interviewed felt that they would take their child directly to the hospital if they believed the child was seriously ill and required treatment beyond the scope of the CHW’s abilities. To them, a serious illness was considered to be a fever with very high temperatures.

*“...if the sickness is not very serious, you decide to take the child nearby [to the CHW]. But sometimes you can see the child is in a very critical condition, then you decide to take the child [to the] hospital.” (Participant f; female)*

We asked caregivers how much they knew about the training the CHW received. While many believed the CHW was trained, their reasoning behind this belief differed. Some mentioned that the CHWs informed them of their training, while other caregivers had seen or heard of the training sessions themselves, or from someone they trusted. Others associated similarities in treatment between what they experienced at a health clinic versus what they experienced with a CHW as proof of training.

*“I compared the treatment given to me when I go to hospitals and the dose the [CHW] gives to us...and I therefore confirmed that these people were trained.” (Participant c;*

*female)*

Others felt the act of testing before diagnosing was proof that the CHW must have certain skills and thus must be trained.

*“She knew what she was doing or else she would only be giving out drugs without first testing the child. But I saw that she knew what she was doing because she would first test the child before giving you drugs... I was not scared... because even other hospitals first test the child before giving out drugs. That only showed me that this woman had skills and expertise in treating children.” (Participant a; female)*

Finally, some felt that CHWs had been trained and were competent to provide care because they had medical equipment. To the caregivers, the fact that CHWs were in possession of diagnostic equipment such as RDTs and record books was evidence of their training and abilities to treat.

*“Because I saw the equipment they gave her to use, to me that showed her ability to give treatment.” (Participant 05; female)*

### **No drugs, no problem**

The caregivers' sense of trust in the competence of CHWs was also reflected in how they sought care from them when testing kits, gloves and drugs were in low supply or out of stock. Despite knowing that the CHW didn't have enough or any drugs or test kits, they still visited the CHW for a diagnosis and advice on how to care for their children. This showed that they did not seek out the CHW only to get free drugs, but because they trusted the diagnosis (with or without tests) and advice of the CHW. Additionally, caregivers spoke about seeking the CHW's diagnosis and advice so that they could purchase the appropriate drugs at the drug shop. Visiting

the CHW, though, may have been viewed as a pathway to receiving drugs through a referral note to the government health centre

*“If she doesn’t have all these drugs, I will go there and she tests my child. Then after knowing the disease the child is suffering from; she will write a note for me.”*  
(Participant c; female)

*“I would still go there to seek advice even when she doesn’t have the drugs. Maybe she can bleed the child and tell me the type of fever the child is suffering from and advise me to take the child to another hospital to receive drugs”* (Participant n; female)

Another factor in seeking care from a CHW may be the caregivers’ dissatisfaction when there were drug stock-outs at the government health centre. Compared to a stock-out for the CHWs in the village, those at the health centre were a major inconvenience to the caregivers from both villages due to the distance of the government health centre from their homes. The following statements reflect the frustration and inconvenience caregivers felt about drug-stock outs at the health centre:

*“OK, our government hospitals are like this; you wake up early in the morning, go to the hospital and stay there for the whole day queuing in a long line. At the end of the day, they tell you that there are no drugs.”* (Participant 11; female)

*“You might go to [the government health centre] thinking that there are drugs since it’s a government hospital, unfortunately after spending transport to go there, you find no drugs.”* (Participant f; female)

## Child recovery

Another factor in the caregiver's perception of CHW competency was the recovery of the child. Seeing their children recover after visiting the CHW emerged as the strongest reason for caregivers to trust in the CHWs.

*"...I trust this program [because] when my child is sick and I take the child there, they become okay. That means I am putting trust in the program that they brought to our villages." (Participant a; female)*

*"Why not trust her when she treats my child and my child recovers?" (Participant 05; female)*

Though some caregivers mentioned initially being hesitant about the CHW's ability to treat, seeing their children's recovery after their visit to the CHW eased any initial fears or concerns they had. It was because their children recovered, that the caregivers then trusted the CHW's abilities to provide good treatment to their children.

*"...I was full of fear that maybe the day will not break before this child dies. But on the following morning, the child was OK and she started drinking and playing, and since that time I started putting trust in that woman." (Participant h; female)*

*"At first I felt very scared...I said to myself "let me just go there and they treat my child" because I had heard often people talking about them. In the end, the child recovered, and then I accepted that these people really knew what they were doing." (Participant c; female)*

*"I brought my child and she treated her and I went and gave the drugs to the child and they got finished, and the child became OK. And since that time I started putting trust in the CHW." (Participant n; female)*



For caregivers who were confident in the CHWs' skills, positive treatment outcomes reinforced their trust in the CHWs' competence, and encouraged them to return:

*“If you go there (to the CHW) and she treats the child and the child recovers, there the trust increases” (Participant 1; male)*

*“When I visit the CHW for care and my child recovers, I am definitely encouraged to go back.” (Participant 06; female)*

Furthermore, when their children recovered, caregivers were motivated to inform other caregivers in the village about the CHW and the services. Since word of mouth is extremely important in these communities, the community's positive talk about the CHWs and the services received helped to enhance the overall trust in the iCCM program.

*“When I reached there and I received treatment and the child became OK, I said to myself, “this woman can really treat children.” As I was also told that this woman is treating children, I can now also direct other women to go to that woman to seek treatment.” (Participant g; female)*

An interesting finding was that while initial trust in the CHWs seemed to be greatly influenced by a child's recovery, once that trust was established, caregivers were admittedly more understanding of the CHWs. During the interviews, many caregivers who reported trusting the CHWs due to previous positive experiences alluded to the fact that their child's recovery was not absolutely necessary for the caregiver to continue trusting the CHWs. In the event that their child does not recover, these caregivers mentioned they would still go back to the CHW to get a referral to the government hospital or to consult the CHW and receive advice, which will be discussed in the following section.

*“If the child fails to recover, they refer you. But you can’t blame the CHW... for not taking care of giving treatment to your child.” (Participant e; female)*

*“If you find drugs at the CHW... you give them to the child. In case the drugs don’t work, you can still go back to her for advice.” (Participant f; female)*

On the other hand, one caregiver felt that a negative first experience would have led to mistrust and a reluctance to seek care from the CHW next time.

*“The trust I put in her was because I brought my child to her and the child recovered. If this child had not recovered, I wouldn’t have brought another child to her for treatment.” (Participant n female)*

#### **6.1.2.3 Cognitive competence**

Cognitive competence refers to the CHWs’ abilities to make good judgement calls. The findings suggest that in addition to trusting the CHW’s technical skills, caregivers also trusted their judgement and saw them as individuals from whom to seek advice for a range of problems and concerns.

#### **CHW advice**

It was often mentioned by caregivers that they trusted the CHWs not only because they received warm welcomes and effective medicine, but also because they seemed knowledgeable and gave good, useful advice. This advice, sometimes went beyond basic medical advice regarding the child’s condition for which they were visiting.

*“I trust [CHWs] depending on the treatment they give us plus the advice on how to take care of our children.” (Participant 02; female)*

When caregivers followed the advice provided by the CHW, including those outside of iCCM, and saw improvements in their health, these results may have contributed to their trust in the CHW as a health care provider.

*“They sensitize us on how to care for our children to prevent them from getting malaria. They advise us accordingly. If you follow their advice, the child stays healthy. Furthermore, we are grateful for the program because most mothers in this village don’t know how to take care of their children regarding certain diseases that are dangerous to them.” (Participant 09; female,)*

*“I also tried to change the nutrition of the child, as she had told me. I started boiling water for the children and changed their diet as per the CHW’s recommendations and now I see my children having good health.” (Participant 14; male)*

Some caregivers who did not have a sick child would still go to the CHW for advice regarding other concerns. The caregivers considered the CHW to be knowledgeable and someone whose opinion could be trusted, not only for matters relating to health.

*“I went there to seek advice on how to look after the baby’s umbilical cord and other things. Yes, [I knew] drugs were out of stock. I wanted the CHW to give me advice...” (Participant 02; female)*

*“...she’s even a marriage counsellor! <laughs> She gives us advice on marriage, [so] there was no way I would get worried.” (Participant e; female).*

## 6.3 Factors influencing trust in CHWs

Three important factors external to the CHW were found to influence the levels of trust caregivers have in CHWs. First, was the role of broader provider-community interactions. Second, were how CHWs were viewed and positioned by authority figures. Third, was how the CHW was integrated into the structures and expectations of the iCCM program itself. The first two were enablers of trust while the third factor sometimes acted as a barrier to building trust. Of the factors internal to the CHW, such as caregiver demographics, only gender, motherhood and literacy were mentioned by caregivers.

### 6.3.1 CHW demographics

Caregivers stated preferring and more trusting of older, mature women who have had children, which may be due to the perceived empathy from such individuals who understand the challenges in child-raising:

*“Those ones who have not yet given birth will not manage. It needs a woman who has given birth and has experience and responsibility of looking after children, and to know how another feels when her child is sick. Those are the people we need.” (Participant 08; female)*

*“An adult is so much aware of what she’s doing besides she would have given birth and know when the child is badly off and hurry to treat the child compared to a young adult who might not be knowing anything.” (Participant 06; female)*

Literacy was mentioned as being an important skill for CHWs, however most caregivers did not feel that a high level of education - beyond a basic ability to read and write - was essential to be a good CHW. Instead, emphasis was placed on other attributes, such as the CHWs' caring, empathy and general good conduct. Caregivers valued someone who they saw as a good person who showed concern for their children more than someone who was educated.

*"For me, [this] is how I look at it: There is one who is educated but treats you very well and there's another one who is educated and she just looks at you as good for nothing."*  
(Participant n; female)

*"Having good characters in welcoming people; being empathetic about people in problems; being concerned about sick people; things like that. But you [can] come across an educated person feeling very proud and not caring at all."* (Participant m; female)

### **6.3.2 Broader CHW-community interactions**

In the villages, interactions between the CHW and the community were found to have a strong influence on levels of trust that caregivers have in the CHWs. In particular, the part that the community played in selecting the CHW, and the CHW's reputation in the village were important in establishing the CHW as being trustworthy.

#### **6.3.2.1 Community selection**

The fact that the community chose the CHW from amongst themselves influenced the levels of trust caregivers placed in the individuals chosen. Because they were from the same community, CHWs shared the same socio-cultural and economic attributes as the caregivers. The

resulting familiarity and sense of “sameness” may have contributed to the caregivers feeling more comfortable with, and trusting of, the CHWs compared to the trust they would have in an outsider.

*“I do trust them...Because they are my people.” (Participant f; female)*

*“...if our languages and culture aren’t the same or you just came to the village; I can’t trust you” (Participant 14; male)*

No difference in attitudes towards the CHWs was found among caregivers who were absent during the CHW selection. These caregivers stated being happy with the CHWs, and that they trusted their community’s decision in choosing a person who would make a good CHW for the village. Caregivers reported a strong sense of trust in their community at large, which helped the development of initial trust in the CHWs based on the judgment of their peers.

*“By the time they [the community] assign any responsibility to someone they must have trusted him / her because s/he is a good person in the village. They trust that person to do the job.” (Participant m; female)*

*“The community saw that those people were trustworthy, hardworking, and they’re people known or easily approachable.” (Participant l; male)*

#### **6.3.2.2 CHW reputation**

The reputation of the CHW amongst the community members was also an important factor in caregiver trust. Both the reputation of the CHW as a person in the community, as well as the reputation of the CHW in the role of a health provider had an impact on the caregivers’ attitudes towards the CHW. A positive reputation engendered trust and was an important factor

in the caregiver's decision on whether to bring their child to the CHW or not. Caregivers acknowledged that information, either good or bad, travels quickly in the villages. In general, the CHWs had a good reputation among caregivers in the two study villages.

### **Reputation as a person**

Most caregivers acknowledged knowing or knowing of the CHWs in their villages prior to their selection for the position. In both villages, caregivers told us that the CHWs were selected by the community at a meeting organized by the village chairperson. CHWs were stated to have been chosen because of their previous experiences and how the community perceived them. Because they all lived in the same community, most caregivers knew the CHWs' personalities and how they interacted with others in day-to-day life. Caregivers stated they trusted these individuals in the CHW position because of what they knew about them socially, and as people with a good character. It is apparent that personal characteristics were very important, as described in the loyalty dimension, and the structure of the community allowed for the knowledge of these personal characteristics to play an important role.

*"I knew her as a person, as a woman...I even knew her behaviours; she wasn't a bad person. I knew her as a good person; a mother." (Participant 10; female)*

*"I trust them [because] I [grew up] here. I was born in this village and know whatever is going on in their lives. You know their social life and how well they relate with people." (Participant 09; female)*

*"Her lifestyle is good. She doesn't walk at night, she doesn't get involved in people's affairs by asking "why have you done such and such a thing", she counsels the*

*community on their code of conduct, in addition she tries to counsel people's children. Her character is good.” (Participant e; female)*

In addition, caregivers stated they chose who they saw as fit for the position based on their previous knowledge of their past job experiences, and how responsible they were. For example, one caregiver mentioned how one CHW worked with programs related to children's rights and nutrition, and how that increased her trust in that person:

*“Some time back, she was working with a program which advocates for children's rights and nutrition in this parish... she was hardworking and we noted that. She again worked with another project for children; there we developed more trust in her because she was involved in many activities in addition to being hardworking.” (Participant 02; female)*

In this study, two caregivers out of the total 28 caregivers interviewed expressed distrust in a CHW because of their belief that she occasionally drank alcohol. They worried about the possibility of going to her house to get medical attention only to find her not in her best frame of mind to treat their children. These two caregivers did not express any dislike towards this CHW as a person or did not question her moral character. However, they stated to prefer bringing their children to the other CHW, who to their knowledge did not drink. One caregiver explained why she decided to visit the other CHW instead:

*“OK, the first time I went there my child was treated and recovered. The second time I visited her, I was demoralised because the CHW had taken alcohol. I got worried and said, does this CHW treat people's children when she has taken alcohol?! She will [make] mistakes or give wrong instructions to caregivers when dispensing drugs to them. I made up my mind not to go back to her.” (Participant 09; female)*



The caregiver knew that this CHW sometimes drank, but that she had never seen the CHW drunk. However, knowing this CHW does drink, the caregiver expressed worry that she could make a mistake if performing a blood test, which may be considered more technically challenging than other diagnostic acts like measuring temperature or breathing rate.

*“There are times when she takes some drinks...and if you go there when she has drunken some alcohol you’d feel fearful. For instance, if you bring a child suffering from malaria and it necessitates to bleed the child; there you fear that maybe she will make mistakes... I have never found her drunk, but she drinks sometimes.” (Participant 12; female)*

It is important to note that these two caregivers did not talk about the CHW as being generally unfit for the position. Rather, the concern seemed to be about not knowing when she may or may not have had an alcoholic beverage. It is also important to note that their views towards this one CHW did not affect their attitudes towards the other CHW in their village. While the rest of the caregivers interviewed from that village (twelve out of the fourteen) did not express any concerns or negative feelings regarding this CHW, they may have been simply unaware that she drank alcohol.

### **Word-of-mouth reputation as a CHW**

Many caregivers visited the CHW because of positive stories they heard from other caregivers who had brought their child to the CHW. Caregivers told us how they heard about the drugs and the good treatment from other caregivers, which influenced their decision to go to the CHW. Positive word-of-mouth throughout the village created comfort and acceptance of the CHWs, and helped lay a foundation of initial trust among those who had never visited them.

*“For me I was told by the neighbours that these people are offering good treatment. So I also went there...” (Participant 14; male)*

*“No, I wasn’t [worried]. Reason being, many people had told me that drugs were available and helped children to recover. Before I had gone there for the first time, my village mates used to say that drugs were available at the [CHW’s] and helped children. That’s what forced me to go quickly without any fear for treatment.” (Participant e; female)*

*“I trust them, [because] I have never heard any bad thing about them.” (Participant l; male)*

Not all caregivers were convinced about the CHW based solely on their good reputation. Many participants who spoke about being recommended to the CHW admitted that they were tentative at first about their ability. Though they had decided to visit the CHW based on positive word of mouth, they needed to see for themselves what the CHW and the treatment was like prior to fully trusting the CHW. As one caregiver explains:

*“At first I was hesitant that maybe things will not go well, as I had not gone there before. But when I reached there, things were OK, and that was what forced me to go back. I felt settled that the service was good and worth trusting.” (Participant c; female)*

### **6.3.3 Authority as a factor influencing caregiver trust**

Trusted authority figures were found to play a role in influencing caregiver trust in CHWs. Caregivers mentioned various sources of authority as reasons why they visited, or felt more comfortable going to the CHWs. These included the recommendation of health centre workers, the CHWs’ connection to health centres and their belief that it was a government run

program. This factor encompasses the “institutional trust” factor listed in the conceptual framework as the institutions listed, such as the government, are figures of authority.

#### **6.2.2.1 The government**

Many caregivers commented that they believed the iCCM program was initiated by the government, or that the government had supplied the drugs to the CHWs, therefore it must be a trustworthy program. They believed the government wouldn’t implement anything that would do them harm, and that it would ensure that the CHWs are properly trained.

*“...we think they know what they’re doing because the government trusted them”  
(Participant 13; female)*

*“The government cannot do something that can lead to the death of its citizens and they entrusted this responsibility to the CHWs because they trusted that they will do good things. That’s what made me feel settled...I knew that whatever they will do will be what they were trained to do.” (Participant c; female)*

In addition, caregivers were happy with the quality of the drugs given by the CHWs. Many considered the CHWs’ drugs as “government drugs” which they trusted, and since CHWs were entrusted with these drugs, caregivers felt they could thus trust the CHWs to treat their children:

*“I was forced to go there without having any worries in her because she was using government drugs to treat children. She collects them from the government, so she must work as a nurse who was trained to perform.” (Participant k; female)*

Government announcements on the radio acknowledging the CHWs' work and encouraging caregivers to go to them positively influenced caregiver trust in the CHWs' abilities and services. Caregivers spoke about the radio announcements for CHWs that advised caregivers to first go to the CHWs before visiting the health centres or hospitals. Radio is a main source of information and news, and caregivers assumed that the announcements about the CHWs were from the Ministry of Health or some other governmental authority.

*“They always say it on radios; before going to hospitals, care givers should first visit the CHW...that’s why I trusted them” (Participant 06; female)*

*“They sensitize people on the radio about these CHWs...this brought me a feeling that these people really know that they are doing. (Participant 04; female)*

#### **6.2.2.2 Connection to health centres**

Staff at the government health centre for both study sites honoured referrals from CHWs as per the Uganda VHT Strategy mandate, and nurses at the health centre acknowledged and asked about the iCCM CHWs. This clear connection between the village CHWs and government health centres gave the CHWs' credibility. To the caregiver, it proved the legitimacy of the care CHWs provided in village. This connection also linked the CHWs to the larger health care system in which there is existing institutional trust. Caregivers were encouraged to seek services from the CHWs because nurses also put their trust in the CHWs and their supplies. Some caregivers stated that health centre staff informed them about, or recommended them to visit the CHW in their village. Staff at the health centres also confirmed the suitability and effectiveness of drugs available from the CHW and assured caregivers that they were supervising the CHWs.

*“Even when the child doesn’t respond to the drugs quickly and you [go to the] government hospital, they first ask you if you got any drugs from the [CHW] and they tell you to first give the child those drugs.” (Participant 04; female)*

*“We were told by those people from [the government health centre]; they came and told us [about the CHWs].” (Participant d; female)*

*“OK, the first time I went to [the government health centre was] when the child had cough and was feeling feverish, the child was badly off and the doctor asked me why I had taken the child there when the drugs were in the villages. Then I came back and asked and they told me about [the CHWs].” (Participant 12; female)*

*“Even when you visit a government hospital, they tell you that the drugs the [CHW] gave the child are the ones going to help the child recover.” (Participant 04; female)*

*“The nurse at the hospital assured me that they will work with CHWs...This gave me confidence that the CHWs will be supervised by qualified nurses.” (Participant 13; female)*

It is likely that these endorsements from trusted medical staff were found to positively influence caregiver trust in the CHWs. Although many caregivers expressed negative sentiments towards the lack of respect and negative attitudes received at the health centres, their trust in the competence of the health workers was strong.

The connection to the institutions was enhanced by the referral form that CHWs provided to caregivers who needed to go to the clinic. The advantages of having a referral form was mentioned by almost every caregiver without prompting by the interviewer. It was often stated that with the CHW’s referral form, treatment was received quickly once reaching the health

centre, usually because the CHW had done the preliminary diagnosis which the health care workers trusted. As one caregiver put it: *“things become easier for you.”* (Participant 07\_01).

*“...as for the referral form, there’s a nurse [at the government health centre] who works hand in hand with CHWs in villages. That’s the person we go to for treatment when we reach the health unit.”* (Participant 13; female)

*“When you reach the [government health centre] you just show them the note and they will automatically be knowing the disease the child is suffering from because [the CHW] will have written the problem there.”* (Participant 07; female)

*“When you go there with a referral form from a CHW, they give you quick services...you don’t need to first line up for treatment, health workers would be knowing where you took the child when you have a referral form. So, they attend to you immediately, thinking the child might be in a bad state.”* (Participant 09; female)

## **Chapter 7: Discussion**

### **7.1 Introduction**

The purpose of this study was to determine what trust caregivers of children under five have in CHWs providing iCCM services in rural Uganda. As outlined in the methodology chapter, qualitative research methods were used to collect the data from caregivers in two rural villages in Kyenjojo District. First, I present a detailed discussion of the findings in which I revisit the main dimensions and factors influencing trust as reported by the caregivers in this study. Then, I provide a revised conceptual framework for trust in iCCM CHWs in the rural Ugandan context based on findings from this study.

## 7.2 Discussion of the findings

This study contributed to the literature around patient trust in CHWs, and in particular CHWs treating children, through the use of a conceptual framework of trust that builds on work done by others around trust in the provider.<sup>36,52</sup> The use of a conceptual framework allowed for a structured identification of aspects important to different dimensions of trust, and the development of a modified framework for understanding trust specifically in the context of CHWs in iCCM programs in western Uganda. Caregiver trust in CHWs treating their children was examined on two dimensions; perceived loyalty, and perceived competence, and factors influencing aspects of these two dimensions, such as authority figures, broader CHW-community interactions and CHW demographics.

The findings suggest that the perception of loyalty to the caregiver was built on how good the CHW was to the caregiver. This perception was based on the CHW's demonstration of respect, commitment to and prioritization of the caregiver and child's interests and honesty. Perceived CHW "goodness" was found to be influenced by certain CHW demographics. Perceived CHW competence was based on the caregivers' perception of the CHWs interpersonal skills, technical competence such as diagnosis and child recovery, and the feeling that CHWs were giving effective advice. CHW competence was also found to be enhanced by authority figures who acknowledged and supported the CHWs, and to a slight extent by demographics such as CHW literacy.

## **Perceived CHW loyalty**

All the subdimensions of loyalty contributed to the concept of being a good and caring person who could be trusted. The caring attitudes of the CHWs were consistently noted by the caregivers. Being seen as a caring - respectful, committed, honest - individual is important for building trust because it is linked to perceived motivation of the individual; one is more inclined to trust if they perceive the trustee's motivations to be in their best interest.<sup>36</sup> The perceptions of the CHW being a caring person was in part enhanced by the CHWs' good communication skills, something that has been found to play an important role in trust in a literature review on trust in nurses.<sup>42</sup> Caregivers placed emphasis on the fact that CHWs listened to their worries, and took the time to explain procedures and how to administer the drugs to the child. Caregivers felt respected because they believed CHWs were being sincere rather than patronizing in their explanations. The caring nature of CHWs was clearly in contrast with poor experiences they received at the health centres where staff were stated to be rude or condescending.

Building relationships is an important mechanism for trust development<sup>61</sup> and it is well understood in nurse-patient literature that doing so takes time.<sup>42</sup> However, there were some factors that enhanced the relationship between caregivers and CHWs. Because the CHWs were from the community, a basic relationship was already established. The sharing of language, culture and daily way of life made the CHWs relatable, and has been found important in doctor-patient relationships in other studies.<sup>62</sup> The in-person social connectedness of villagers may have been higher in part because there is no TV, internet and very limited use of mobile phones, and so villagers were more likely to communicate frequently in person. As a result, more villagers knew others in their own village. This familiarity with the CHW was quite important for caregiver trust in the CHW; it led to the feeling that the CHWs were connected to the community



and were working for the well-being community members. Similarly, a comparative study looking at trusting relationships in sub-Saharan Africa found that the development of these relationships were stronger if the CHWs were from the same community because patients were more likely to believe they were working in their best interests.<sup>49</sup>

The sense that CHWs were genuinely concerned about the caregiver and their children featured quite strongly. Caregivers reported that the CHWs always attended to them with urgency. Because CHWs prioritized caregivers and their child's needs over their own, caregivers believed the CHW truly cared about their children and their issues. They were thus viewed as reliable child health care providers who take their jobs as CHWs seriously and who could be trusted. The relationship between CHWs and caregivers may have enhanced this prioritization of caregiver needs. Caregivers mentioned feeling that CHWs were empathetic to their needs because they were the same as them, especially if the CHW was a female and a mother. In fact, caregivers stated that there was a preference for females and mothers as CHWs as they would have had similar lived experiences with caregiving and childhood illnesses and would understand their situation and needs better. There was also the stated preference for CHWs who were mature, because age was considered to reflect upon one's level of experience with children and responsibility. The importance of empathy in developing trust was also expressed in a recent literature review of health sector relationships in sub-Saharan Africa.<sup>63</sup> While none of the studies in the review examined relationships between CHWs and patients, it was found that an empathetic attitude helped engender patient trust.<sup>64</sup>

Honesty was important to caregivers in this study, however it did not emerge as a separate dimension as presented by Hall et al, but rather as a subdimension of loyalty as part of the concept of being a caring, good person. Honesty has also been found to be significant to the

development of trust in the literature around trust in health care providers.<sup>4,36,42</sup> While honesty means telling the truth, and avoiding intentional untruths, it can also relate to the competence dimension of trust.<sup>36</sup> This was found to be the case as caregivers stated that the CHWs were honest and upfront about the extent of their abilities to treat children. The CHWs were known to stay within the illnesses they were trained and equipped to diagnose and treat, and within the age limit of 5 years and below. Thus, caregivers felt comfortable knowing that the CHW would not go beyond their technical means to try and treat the child, potentially putting the child at risk. CHW honesty about their limits in medical competence positively influenced caregiver trust.

An interesting contrast was seen in how caregivers referred to poor treatment from nurses and their lack of bedside manners. This poor treatment led caregivers to want to seek care from alternate providers. For some services, CHWs became a good alternative, especially since caregivers received the respect and trust that they wanted from CHWs. However, it may be a negative thing for caregivers to rely too much on CHWs, especially since they are volunteers and there is a risk of overburdening them. The reported negative interactions with government health workers may likely be a result of the health workers being overwhelmed, and the same could happen if the CHWs begin to be overwhelmed.

Patients' negative attitudes towards government health workers may also be due to misunderstandings. A qualitative study<sup>15</sup> looking at Ugandan government health worker perceptions showed experiences of tough working conditions. Health workers posted at rural clinics are often overworked due to shortage of staff, resulting in few or no breaks and little time off. In the study, health workers also spoke about being accused of being slow and unresponsive by waiting patients, when they were really taking a short break, or dealing with important paper work. Some nurses confessed that they were often exhausted and often become irritated when

dealing with patients, against their best intentions.<sup>15</sup> This study did not explore CHW workload and any challenges, hardships or frustrations that they may have experienced. This is an area for further study.

Another aspect of the CHW program that was found to potentially impact caregiver loyalty and thus trust is the expected constant availability of the CHW. We found two caregivers who expressed distrust in a CHW who they knew to occasionally drink alcohol. It is unlikely that the CHW in question was a heavy drinker because these attitudes of distrust were not expressed by the other 12 caregivers interviewed in that village, and a negative reputation such as being an excessive drinker would have been shared widely by word of mouth among caregivers. Rather, this example may point to a larger programmatic issue in which CHWs are considered to always be on-call. The way the program is currently structured, with no set working hours for CHWs compared to formal health care staff, may place undue strain on caregiver-CHW relationships and negatively affect trust if the CHW is unable to meet the caregivers' expectations all the time. What community members deem as acceptable behaviours on or off the clock should be explored further to ensure that these expectations do not negatively impact client trust in CHWs. In addition, CHW programs may also benefit from an exploration of reasonable working hours or how to implement time off for CHWs to avoid overburden and worker burnout.

## **Perceived CHW competence**

In low resource settings, judgements of competency based on formal education may not be relevant due to low general literacy and opportunities for education. In this study, the highest level of education completed by the majority of the caregivers was primary level 7, which may

also reflect the educational status of CHWs. Judgements on health provider competency were thus more likely to be based in shared community opinions around proxies for competence in providing health services such as demonstration of ability to perform tasks, self-confidence and interpersonal relationships. In this study, most of caregivers' medical knowledge was derived from previous personal experiences with the health system, which, along with opinions of friends and relatives and trusted sources, informed their judgments of CHW competence.

Belief in the CHWs' cognitive competence, which refers to the CHWs' ability to make good judgements, is reflected in the positive attitudes towards the CHWs' advice which caregivers found to be effective. Technical competence is in general more difficult for patients to assess<sup>36</sup> and in this study the findings suggest that caregivers ascribed the act of diagnosing and the related task to make the diagnosis, as evidence of the CHWs' technical skills. Most importantly, the child's recovery to health was the strongest determinant of the CHWs' technical competence to treat children under five. A few caregivers had stated that they would still visit a CHW who treated them rudely, if the medical treatment was good. This suggests that trust in CHW technical competency may be a more important dimension of trust than loyalty (specifically, the subdimension of respect), because of the caregivers' concern for their child's well-being.

Caregivers perceived CHW technical competence based on what they saw the CHW do, such as testing the child. From the interviews, it was clear that few caregivers understood what the testing was specifically, but the simple act of their child being tested made them trust the CHW. Similar findings were seen in another India, where laboratory testing was considered a sign of medical competence from patients, because is not routinely performed due to resource constraints.<sup>52</sup> Caregivers compared what they saw CHWs doing with their personal experiences

at health centres, especially the similarities in procedures, testing and even drugs received. These further enhanced caregivers' belief in CHWs' technical skills. Additionally, when CHWs had no drugs in stock, caregivers would still visit the CHW to diagnose their child so that they would know what medication to purchase from local drug shops. Caregivers seemed to trust the CHW's diagnostic competence, and seemed to appreciate the service because it gave them clarity on their child's sickness and allowed them to buy appropriate drugs.

Caregivers also based perceived CHW competence based on what they heard about the CHW from the community. In this study, no differences in attitudes were found among those who were, or were not themselves at the selection meeting. This suggests that CHW selection based on general community consensus (versus personal choice in the selection) had an influence on trust. It also highlights the role of shared community opinions on caregiver judgments of CHW competence. The reputations of individual CHWs as people and as health providers were given serious consideration by caregivers and influenced their trust. This is supported by a study on mothers' trust in community health nurses in rural Ghana in which mothers in the village were found to develop trust in the community nurses based in part on their good reputation as competent nurses and also as good community members.<sup>47</sup> The villages in this study did not appear to have any internal divisions or conflicts and seemed cohesive. Whether the situation would have been different in other less cohesive communities would be interesting to explore, but was beyond the scope of this study.

As mentioned earlier, trust in CHWs' competence was found to be most influenced when caregivers saw their children recover after receiving treatment or effective medical advice from the CHWs. Such positive outcomes reinforced perceptions of competence in a very tangible way for caregivers. Similar observations of the effect of positive outcomes on trust have been

reported in a study on CHWs in Uganda that examined the acceptability of RDTs.<sup>44</sup> An interesting finding was that caregivers who trusted CHWs based on previous positive experiences overlooked instances when the child did not recover after that initial experience. Caregivers did not blame the CHWs, but rather talked about how the CHWs tried their best, and that the child needed to be referred to the hospital instead. Similar findings are echoed in a study in rural India, where patients with an established trusting relationship with their doctor were more tolerant of health provider shortcomings, especially behavioural issues. In that study, tolerance was seen as an indicator of level of trust.<sup>52</sup> Similar findings have also been noted in western settings, where higher trusting patients were more likely to exhibit forgiveness in their physician if they made a mistake.<sup>65</sup> Overall, these findings suggest that early positive experiences are important for establishing trust in CHWs; something CHW programs should take a note of.

Caregivers' perception of CHW competence was also influenced by their understanding of CHW training. While most caregivers didn't know details about the CHW training, they believed CHWs were trained based on the presence of medical equipment, drugs, and because CHWs diagnosed children. CHW literacy had some influence on trust in CHW competence, but only at a basic level. Many caregivers stated that CHWs should be able to at read and write but beyond that, other personal characteristics such as being kind and committed were more important. Finally, CHW competence was enhanced through connections to authority. Caregivers believed the CHWs were provided the equipment by some authority who believed that CHWs were competent to use them, hence it would be safe to trust them.

The role of authority figures emerged as a main factor influencing caregiver trust because of the existing institutional trust caregivers had in the government and the health system. The

acknowledgment of the CHWs and their work by government health workers and government radio announcements indicated to caregivers that the CHWs are part of the larger health system, and gave legitimacy to their work. These all acted to reinforce the CHWs' perceived competence, and caregivers trusted treatment from CHWs because they view CHWs as part of a system they trust in. This finding is echoed in a Ugandan study, which recognized the importance of institutional trust on patients' trust in CHWs; patients were found more likely to visit CHWs if staff at health clinics asked for CHW referral forms, because they felt that meant health workers trust what CHWs do.<sup>28</sup>

Lastly, effective communication was found it to be linked to both perceived competence, and loyalty. This aspect of effective communication has been found to be important in developing trusting relationships in much of the nurse-patient literature.<sup>42</sup> First, CHWs' good interpersonal skills reflected positively upon their competence as child health providers because it demonstrated an ability to gather accurate medical information, and to give patients appropriate information for effective treatment as an indication of medical competency.<sup>36</sup> Second, we saw caregivers praised the CHWs' communication skills as well as their kind bedside manner. Because CHWs related well with both children and caregivers, caregivers and children were comfortable with the CHW, which helped to form trust. In contrast, many caregivers found nurses to be lacking in bedside manners, but still trusted their medical competence. This suggests that while good bedside manners may have helped build trust in CHWs, especially those who are not performing highly technical procedures, poor bedside manner may not have been a strong reason for mistrust.

## **Confidentiality**

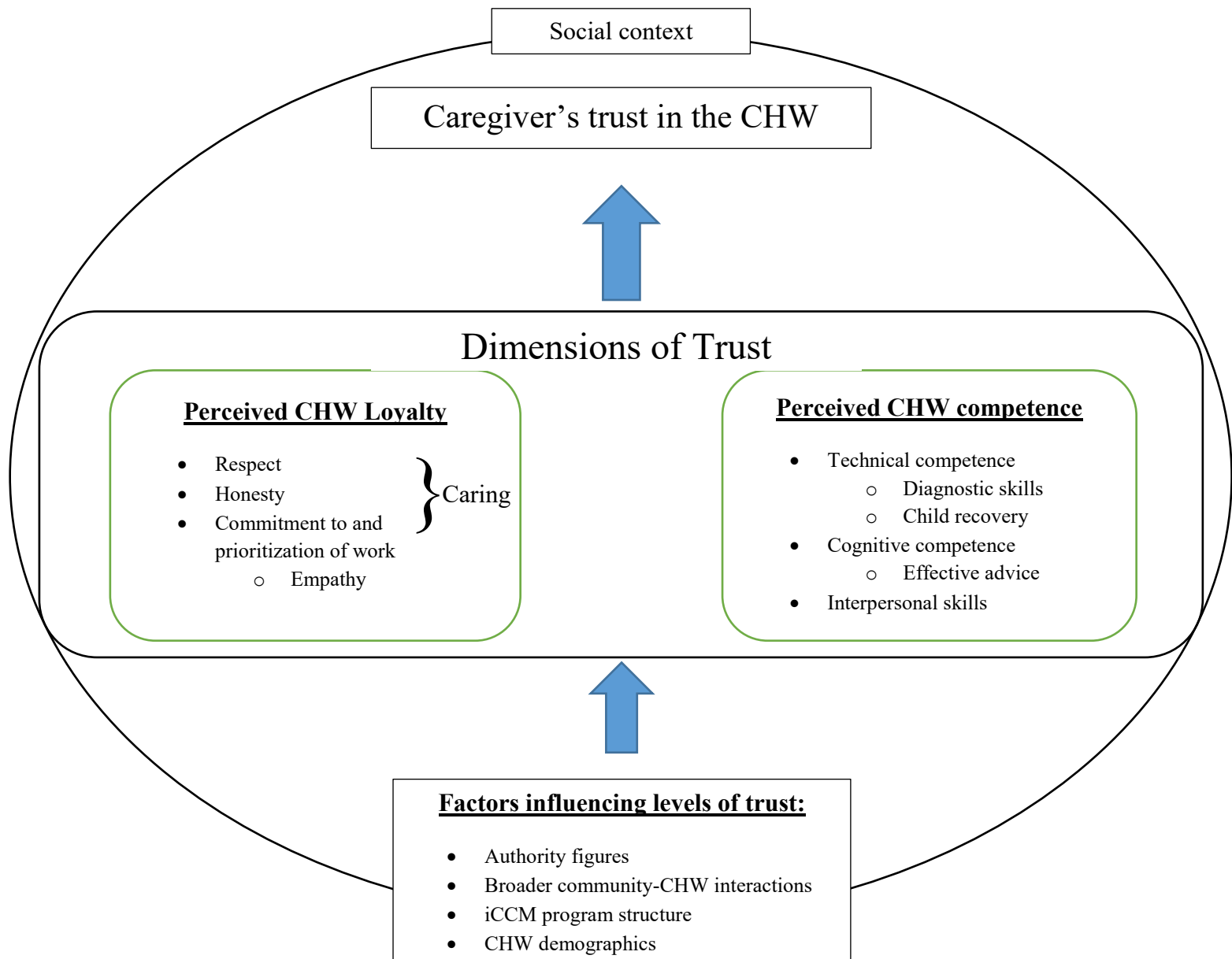
As expected, confidentiality around medical information was not found to be a main dimension in caregiver trust in iCCM CHWs. This was expected since child illness is not typically a confidential topic, therefore caregiver trust in a CHW would primarily hinge on other factors. However, when we asked caregivers to describe what trusting someone means to them in general, an important theme that emerged was the ability for the trustee to keep a secret. Therefore, confidentiality still features as an important factor in trust. Caregivers may still consider personal traits of someone who is not a gossip and keeps secrets as someone they could trust with important issues, such as their child's health. So, while confidentiality around their child's health issues was not a primary concern for caregivers' trust in the iCCM CHW, it still may have played a role in their overall trust in the individual, and consequently in their trust in the CHW as a health provider.



### 7.3 Revised conceptual framework

Below I present a revised conceptual framework of caregiver trust in the CHW that reflects the findings from this study.

Figure 2: Revised conceptual framework for caregiver trust in iCCM CHWs in rural Uganda



## 7.4 Limitations

The language difference between the participants and me is a major limitation in the study. While the topic guide was consistently being revised throughout data collection, receiving translated transcripts to review took time. Therefore, it is possible that some interviews may have benefitted from timely changes in the topic guide. In addition, the language difference meant I had to rely on the note-taker's notes. Subtleties that may have provided more context for the interviews may have been missed, especially if I was not present during the interview. In addition, my presence itself may have influenced how caregivers responded, which is why I decided to stop going with my RAs for the interviews. It is also possible that there was social desirability bias, where caregivers saw the RAs as part of the iCCM program and responded in a way they thought we wanted them to. A study limitation is that we are unable to collect data on caregivers' attitudes outside the interview context.

We only interviewed caregivers who had previously brought their child to the CHW for care, which may have resulted in a bias in attitudes. In addition, the iCCM CHWs in both villages sampled were clearly active in the community and in their role as CHW. Caregiver trust in less engaged CHWs may not be the same, therefore the results might only be transferable to communities with active CHWs. Recall bias may also have come into play because caregivers were eligible for selection if they had brought a child within a two-year time frame. However, this bias was limited as most caregivers had brought children to the CHW much sooner than that because child sickness was a common occurrence.

Though the results provide important and novel insights into the existence and influences of trust that caregivers have in iCCM CHWs working in their villages, they remain limited in

their transferability. Country contexts differ greatly socio-economically and culturally, and in the way programs are set up. However, the study communities are typical of many rural communities in Uganda and therefore the results are likely to be transferable to other similar settings in the country, and perhaps elsewhere in Africa.

## **Chapter 8: Conclusion**

This study was an attempt to deconstruct and examine the dimensions that contribute to caregiver trust in iCCM CHWs, and adds to the limited research on trust in CHWs. Establishing trusting relationships could be key for the success and sustainability of programs that need to expand their reach to those who are currently underserved. The findings suggest that trust in iCCM CHWs is strongly influenced by certain subdimensions within caregiver perceived CHW loyalty, and caregiver perceived CHW competence, and that the dimensions do not act in isolation. Perceived CHW empathy and overall caring, in addition to the CHW's technical competence proven by the child's recovery were the strongest subdimensions of trust. In addition, good interpersonal skills were instrumental to both perceived competence, and perceived loyalty because those with good communication skills can better convey respect, empathy and care. On the other hand, the subdimensions of honesty and cognitive competence were not as influential on their own, but were found to contribute to the overall dimensions of trust. Caregivers believed it important to choose someone who they thought was a trustworthy individual based on a good reputation within the community, and previous experiences. Existing high trust in fellow community members, and positive word-of-mouth engendered pre-existing trust in the CHWs.

This study adds to an understanding of trust in this context and type of CHW program. More research would be required to see if these findings held in other contexts or different types of programs. Other dimensions of trust, such as confidentiality, may play a stronger role in patient trust if the program is not focused on the health of the child. The influence of factors such as community cohesiveness, and caregiver or CHW demographics may also emerge more strongly in different social contexts.

Providing CHWs with training that focuses on engendering trust from communities can help make CHW programs more effective by improving health seeking behaviours. Based on my findings, in addition to the basic medical training CHWs receive, focus should be placed on interpersonal skills, such as and how to interact with new or recurring patients and children. CHWs should be trained on how to best explain to patients the procedures and how to administer medications, as well as making sure the patients feel heard. This includes being patient, and taking the necessary amount of time to explain things. Caregivers in this study appreciated feeling sincerely welcomed in the CHW's home, and an aspect of that was being offered somewhere to sit. It would be worthwhile to ensure that CHWs have an area in their home where they can welcome clients comfortably by providing examples of how to do so in their own home situation, using what they already have. The dependability of the CHWs were also highly regarded. Training should emphasize that CHWs should attend to patients in a timely manner, however it would be important that CHWs know this may not always be achievable, and how to professionally address such situations. CHWs equipped with the knowledge and the interpersonal skills to handle these situations pleasantly are more likely to be perceived as competent, professional and trustworthy.

On a broader scale, authority figures such as the government and health system should continue to legitimize and give strength to CHW programs. Communities should continue to be encouraged to select their own CHWs by popular vote and without influence from authorities or people of power. Findings from this study suggests that CHWs working in child health programs, should be selected based on certain characteristics, including effective interpersonal skills, perceived goodness and caring, a basic level of literacy, and experiences as a mother. Lastly, iCCM programs work best when caregivers feel comfortable accessing services from both the CHWs and health workers. The mistrust in health workers caused by poor service is an area of concern for the success of CHW programs, and will require continued attention at the health system level.

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# Appendices

## Appendix I: Interview 1 topic guide (English version)

### Demographic questions to ask caregivers at the start of interview 1:

1. What is your name? (*for conversation purposes only – will be removed in transcripts*)
2. What is your age?
3. What is your marital status?
4. How many children do you have, and what are their ages?
5. Do you look after the children of anyone else? If so, what are their ages?
6. What do you do for work?
7. What is the highest level of education you've achieved?
8. How long have you lived in this village for?

### Contextual information to better understand the relationship to the VHT:

1. Please tell me about the iCCM VHT in your village (who they are, how long you think they've been working as a VHT, etc).
2. Overall, how do you feel about the iCCM VHT program and the services they provide?
3. Why do you think this person was chosen to be the VHT?
  - a. [Probe] What is their character like?
4. How close is your friendship with the VHT? [*or: How well do you know your VHT?*] [*or: Describe your relationship with the VHT*]
5. Is this someone you trust? Tell me why or why not.

### Understanding care, respect and empathy:

1. Tell me about the *most recent time* you brought your child to the VHT for care. How was the visit? Why did you bring the child?
  - a. Probe: What did the VHT do? What was the outcome of the visit?
2. How did the VHT make you feel?
  - a. Probe: Did the VHT seem caring and concerned for the child? How did s/he show his/her care?
  - b. Probe: Did the VHT treat you with respect? Seek examples. Is/was it important or necessary that the VHT treats you with respect? What might have led to VHT treating or not treating you with respect?
  - c. Probe: Does the age of the child matter in your decision to go to the VHT for care? How do you feel about bringing a child under 1 years old compared to an

older child? Explore through asking reasons, and perhaps examples.

3. Now, please think about the *first time* you ever brought your child (can be the same as above or another child) to the VHT. How was that visit? How do you remember the VHT making you feel?

Probe: How does the earlier visit compare to the most recent visit to the VHT? Do you feel differently towards the VHT now? If so, please elaborate why.

#### **Understanding competence:**

1. Please describe the services the VHT provided during your visit

Explore: Did they have confidence that the VHT knew what he/she was doing and why they felt that way.

- a. Probe: What types of characteristics do you think make a person good at doing this job? Is your VHT lacking in any of these characteristics? How much does this matter to you?
- b. Probe: Did you feel that the VHT made any mistakes?
2. When your child is sick, what, if any, are other sources of care available to you?
  - a. Probe: Explore how this affects their decision to seek care from a VHT.
3. Why did you choose to go to the VHT? Would you have preferred to take your child directly to the clinic [or wherever]?
  - a. Probe: Explore how much trust factors into this decision.
4. If you were giving advice to someone about how to be a good VHT, what would you say?

## Appendix II: Interview 2 topic guide (English version)

*\*small talk...make mom comfortable\**

*Thank you so much for having us \*NAME of mother\* (important to say out loud for the recording). Today we would like to hear your opinion on a few more things, and maybe get some clarifications from what you told us last time. Is that OK?*

1. To start, can you please tell me what “trusting” someone means to you?
  - a. PROBE: Who are people you trust, and why do you trust them?
2. Now, I’d like to ask a few questions about your community:
  - a. How many of your village-mates do you know?
    - i. PROBE: explore how difficult it was to get to know them (to get an idea of why they gave the number they did)
  - b. How close is the community? For example, do you help each other in times of need?
    - i. PROBE: how do you help each other?
  - c. How trusting are you of people in your community?
    - i. PROBE: how comfortable would you be if they made decisions on your behalf? (for example choosing a VHT, would you trust them to look after your child while you are away? Would you trust them to look after your possessions or money?)
3. How well did you know the VHT before she was chosen for the job?
4. I want to ask you about the program that treats children < 5 (iCCM) in this village. Who do you think started the program? How does it matter to you?
  - a. You believe it is run by “X Y Z”, does that affect your trust in the program?
5. What do you think the VHT would do if she made a mistake when diagnosing, or treating your child? *Do you think the VHT would be honest with you if they made a mistake?*
  - a. *If the mother says the VHT will not disclose the mistake, ask her how that affects her trust in the VHT. How does that make her feel?*



## Appendix III: Consent form (English version)

**MAKERERE UNIVERSITY**  
**SCHOOL OF PUBLIC HEALTH**



**UNIVERSITY OF ALBERTA**

### Consent Form for Interview

**Title of Research Study:** Exploring mothers' trust in community health workers in rural Uganda  
**Principal Investigator:** Elizabeth Yue, University of Alberta, Canada (eyuel@ualberta.ca)  
**Supervisor:** Dr. L. Duncan Saunders, University of Alberta, Canada (duncan.saunders@ualberta.ca)  
**Uganda Researcher:** Dr. Esther Buregyeya, Makerere University, Tel: 0752 420 555  
**Makerere University School of Public Health IRB Chair:** Dr John Ssempebwa, Tel 0772 963 074

**Study Purpose:** The purpose of this study is to examine the trust that primary caregivers of children under 5 years old have in Village Health Team members who provide care for malaria, diarrhea and pneumonia to children under 5. We hope that the findings will help improve VHT programs.

**Procedure:** If you decide to participate in the interview, a trained interviewer will ask you questions about how you feel about the VHT that cares for your sick child in your village. We will ask you about the times you have brought your sick child to the VHT and about the trust you have in the VHT. The interview will last about 45 to 90 minutes and will take place in a convenient location in your village. If it is OK with you, the interview will be audio taped. If you do not wish to participate, please inform the interviewer.

**Benefits:** There are no direct benefits from participating in this study. However, your answers may help improve VHT programs.

**Risks:** There are no expected harms from participating in this study. If you do not feel comfortable with any of the questions, you can choose not to answer the question or stop participating in the study at any point in time.

**Confidentiality:** To make sure your answers are kept confidential, we will:



1. Ensure that your name will not be shared by us at any time, to anyone.
2. The research team will be required to sign a document stating that they will keep all information confidential.
3. Any reports published as a result of this study will not identify anyone by name.
4. The information provided, including the audio recordings, will be kept in a safe place for at least five years after the study is done. Electronic information will be encrypted and stored on secured computers. Hard copies will be stored at the University of Alberta project office in Fort Portal or destroyed when digitized.

**Freedom to withdraw:** You do not have to participate in this study if you do not wish to. You can withdraw from the study up to 24 hours after the interview.

**Contact:** If you have any questions or concerns, you may contact Dr. Esther Buregyeya at Makerere University at 0752 420 555. Concerns or questions about participant rights regarding this study can be forwarded to the Makerere University School of Public Health IRB Chair: Dr John Ssempebwa, Tel 0772 963 074.

The plan for this study has been reviewed for its adherence to ethical guidelines by a Research Ethics Board at the University of Alberta. For questions regarding participant rights and ethical conduct of research, you may contact the University of Alberta Research Ethics Office at +1780-492-2615.

<b>To be completed by the research participant:</b>	<b>Yes</b>	<b>No</b>
Do you understand that you have been asked to be in a research study?	<input type="checkbox"/>	<input type="checkbox"/>
Was the study explained to you directly or through a document that you could read?	<input type="checkbox"/>	<input type="checkbox"/>
Do you understand the benefits and risks involved in taking part in this research study?	<input type="checkbox"/>	<input type="checkbox"/>
Have you had an opportunity to ask questions and discuss this study?	<input type="checkbox"/>	<input type="checkbox"/>
Do you understand that you are free to withdraw from the study at any time without having to give a reason?	<input type="checkbox"/>	<input type="checkbox"/>
Has the issue of confidentiality been explained to you?	<input type="checkbox"/>	<input type="checkbox"/>
Who explained this study to you? _____		

I agree to take part in this study:		YES	<input type="checkbox"/>	NO	<input type="checkbox"/>	
Signature (or thumbprint) of Research Participant: _____						
Printed Name of Participant: _____						
Date: _____						
Signature (or thumbprint) of Witness (if available): _____						
I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.						
Signature of Investigator or Designee: _____						Date: _____
<b>A COPY OF THIS DOCUMENT IS TO BE GIVEN TO THE RESEARCH SUBJECT</b>						

## Appendix IV: Consent form (Rutooro version)



**MAKERERE UNIVERSITY**  
**SCHOOL OF PUBLIC HEALTH**



**UNIVERSITY OF ALBERTA**

### Formu eyokwikiriza okukaguzibwa

**Omutwe gwokuseruliriza:** Kuseruliza habwesigwa bwabakazi abarukuzaara baina omubakozi beby'Obwomeezi omubantu aba bulikiro omubyaro omu Uganda  
**Owarukuseruliriza omukuru:** Elizabeth Yue, University of Alberta, Canada (eyue1@ualberta.ca)  
**Owarukuroterra** Dr. L. Duncan Saunders, University of Alberta, Canada (duncan.saunders@ualberta.ca)  
**Owarukuseruliriza omu Uganda:** Dr. Esther Buregyeya, Makerere University, Tel: 0752 420 555  
**Mukuru w'Entebe w'akatebe akarukuseruliriza, School of Public Health, Makerere University:** Dr John Ssempebwa, Tel 0772 963 074

**Ekigenderewa kyokuseruliriza:** Ekigendererwa ky'okuseruliriza kunu kiri okwekebiija habwesigwa bwabantu abarukuroterra abaana abali hansi yemyaka etaano obu bainamu aba VHTs abarukuhayo obuhereza handwara y'omuswiya, okuturuka hamu nokuhaswa habaana abali hansi yemyaka etaano. Nitunihira ngu ebiraruga omukuseruliriza kunu nibiija okukukonyera omukusemezamu entegeka za VHT.

**Ebyokuhondera:** Obu oracwamu okwetaba omukukaguzibwa kunu, owarukuseruliriza omutendeki naija okukukaguzi ebikaguzo nkoku orukwehurra hali VHT owarukuroterra omwaana waawe omurwaire omukyaro kyaawe. Nitwija okukukaguzi emirundi wakaleetera omwaana hali VHT kandi nobwesige obwainamu VHT onu. Okukaguzibwa kunu nikwija okumara nkedakika 45 okuhika hadakika 90 kandi nikwija okuba omukikaro ekirungi omukyaro kyaawe. Iwe obu orakigonza, okukaguzibwa kunu nikwija okukwatwa haturambi. Obu oraba otarukugonza okwetaba omukukaguzibwa, nosabwa okumanyisa owarukukaguzi.

**Ebyomugaso ebirumu:** Tiharoho ebyomugaso ebyamaani okuruga omukwetaba omukukaguzibwa kunu. Ebigarukwamu byaawe nibisobora okukonyera omukusemezamu entegeka eza aba VHTs.

**Ebizibu/Ebirukutinisa:** Tiharoho ebizibu rundi ebirukutinisa ebirukutekerezebwa kurugirra omukwetaba omukuseruliriza kunu. Obu otayehurre kurungi habwekikaguzo kyoona, nosobora okusaraho okutagarukamu ekikaguzo rundi okwemereza okwetaba omukuseruliriza obwire bwoona.

**Okulinda ensita: Okurorra kimu ngu twalinda ebigarukwamu byaawe nkensita, nitwija okukora binu:**

1. Okurorra kimu ngu ibara lyaawe tiryamanywa omuntu weena,
2. Abali hakatebe kokuseruliriza nibaija kusabwa okutaho omukono handagano yokulinda amakuru goona nkensita.
3. Ebihandiiko byoona ebirukukwata hakuseruliriza kunu tibiryoleka ibara ly'omuntu lyoona.
4. Amakuru agalihebwayo, obu otairaho namakuru agalikwatwa hantambi, galyahurwa omukikaro ekirungi okumara nk'emyaka etaano kuseruliriza kuhoire. Amakuru agandi halyahurwa ha Computer ezirukwesigwa. Amakuru agahampapura galyahurwa omu office eya University of Alberta, Fort Portal, hanyuma gahwerekerezibwe.

**Obugabe obwokuleka:** Torukuhambirizibwa okwetaba omukuseruliriza kunu kakuba oba otakukigonza. Nosobora okwerekera okwetaba omukuseruliriza kunu nobu harukuba hahaireho esaaha 24 omazire kukaguzibwa.

**Owokuhihikaho:** Obu oraba oine ekikaguzo kyoona rundi ekintu ekikukwasireho, osobora okuhikaho Dr. Esther Buregyeya kuruga mu Makerere University hasimu 0752 420 555. Ebikukwasireho rundi ebikaguzo ebirukukwata habugabe bwabo abanyakwetabire omukuseruliriza kunu bisobora okusindikwa omwa Mukuru w’entebe owakatebe akarukuseruliriza, School of Public Health Makerere University: Dr. John Ssempebwa, Tel 0772-963074.

Entegeka eyokuseruliza kunu ikirizibwe okuhondera ebiragiro nemikorre aba Research Ethics Board omu University of Alberta. Habwebikaguzo ebirukukwata habugabe bwabo abanyakwetabire omukuseruliriza kunu kandi nokuseruliriza okurungi nosobora okuhikaho aba University of Alberta Research Ethics Office at +1-780-492-2615.

Nijuzibwa ugu owayetabire omukuseruliriza:	Ego	Nangwa
Noyetegereza ngu osabire okwetaba omukuseruliriza kunu?	<input type="checkbox"/>	<input type="checkbox"/>
Bakakusoboraho okuseruliriza kunu rundi okatunga ekihandiiko ekiwayesomiire wenka?	<input type="checkbox"/>	<input type="checkbox"/>
Noyetegereza ebyomugaso rundi ebirukutinisira ebiri omukwetaba omukuseruliriza kunu?	<input type="checkbox"/>	<input type="checkbox"/>
Okatunga omugisa ogwokukaguzo ebikaguzo nokubazaho okuseruliriza kunu?	<input type="checkbox"/>	<input type="checkbox"/>
Noyetegereza ngu oina obugaba okuleka okwetaba omukuseruliriza kunu obwire bwoona kandi otahaireyo nensonga yoona?	<input type="checkbox"/>	<input type="checkbox"/>
Bakusoborolireho ebyokulinda ensita?	<input type="checkbox"/>	<input type="checkbox"/>
Noha yakusobolireho okuseruliriza kunu? _____		

Ninyikiriza okwetaba omukuseruliriza kunu:	EGO <input type="checkbox"/>	NANGWA <input type="checkbox"/>	<div></div>
Omukono (rundi ekinkumo) ogwayetabire omukuseruliriza:	<div></div>		
Ibara ly’owayetabiremu omubyapa:	_____		
Ebiro by’okwezi:	<div></div>		
Omukono (rundi ekinkumo) ekya Kaiso (obu araba aroho):	_____		
Ninyikiriza ngu omuntu owataire omukono ha Formu enu nayetegereza bintuki ebinyakuli omukuseruliriza kunu kandi naikiriza uwe wenka okwetabamu.			
Omukono ogw’Owarukuseruliriza:	_____	Ebiro by’okwezi:	_____
<b>KOPI Y’ORUPAPURA RUNU NIJA OKUHEBWA OGU OWAYETABIRE OMUKUSERULIRIZA</b>			