

Exploring the similarities and differences of the perceptions of participation in clinical research in the East African community in King County, Washington.

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**Abstract**

Exploring the similarities and differences of the perceptions of participation in clinical research in the East African community in King County, Washington.

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Purpose/Background: Recent research at Seattle Children’s Hospital by O’Connor (2013) estimates that the prevalence rates of Type 1 diabetes (T1D) are nearly four times higher in East African immigrant youth who receive care at Seattle Children’s Hospital compared to non- immigrant black youth in King County. Most health care providers and clinicians believe the scarcity of available data about African migrants’ health is the real health barrier faced by these populations (Homer et al, 2007). Furthermore, African migrants including East African communities have lower rates of clinical research participation (O’Connor, 2013) East African communities in King County comprise people from diverse origins. While they share some things in common, combining them into one group may be too overreaching and may ignore important nuances that differentially impact participation in clinical research. This study explored the differences and similarities in perceptions towards clinical research and Type 1 diabetes (T1D) both barriers and motivators in these communities relating themes culture, religion and trust.

Methods: Given the limited data available to guide researchers in recruitment of East African communities in clinical research, we used key informant interviews and focus group discussions. Key informant participants were defined and identified as individuals with considerable experience and expertise in navigating the U.S. healthcare system. Purposeful sampling was used to recruit the focus group participants, because of the common characteristics shared by this population (Sandelowski, 1995). Semi-structured interviews were led by a Somali researcher and observed by a non-community researcher. The two researchers who were present during key informant interviews and focus group discussions also conducted the analysis. Transcripts were coded separately by both researchers using Atlas.ti v.7 to organize the data.

Results: The data revealed 3 themes related to barriers and 2 themes related to motivators to clinical participation among these three East African communities living in Seattle and King County. Barriers identified by participants fell into three themes: Cultural, Religion and Trust.

Conclusions: Findings of this study suggest East African communities in King County, Washington have more commonalities than differences relating to perceived barriers and motivators to participating clinical research. There was agreement across the three communities that culture; religion and trust impact their participation in and perceptions of clinical research, yet they differed in their beliefs about how barriers evolved. They all agree educating their community about the benefits of clinical research and future opportunities to participate in clinical research will lessen doubts about clinical research amongst East Africans.

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## **DEDICATION**

To my wife, Hibaq Ahmed Sudi, your love is what I breathe.  
To my family, friends where ever you are in this world, your love is with me always.  
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## **Introduction**

Recent research at Seattle Children's Hospital by O'Connor (2013) estimates that the prevalence rates of Type 1 diabetes (T1D) are nearly four times higher in East African immigrant youth who receive care at Seattle Children's Hospital compared to non-immigrant black youth in King County (6.76/1000 vs. 1.74/1000). Unfortunately there is no available data explaining the reason for this trend. Previous research shows that most African immigrants never had the opportunity to get diagnoses nor get treatment for acute and chronic conditions in their native land due to low or non-existent preventative health care systems (Homer et al, 2007). In addition, East African migrants might be more likely to have chronic conditions that were never diagnosed when compared to native-born African Americans (Homer et al, 2007). Most health care providers and clinicians believe the scarcity of available data about African migrants' health is the real health barrier faced by these populations (Homer et al, 2007). Furthermore, African migrants including East African communities have lower rates of clinical research participation (O'Connor, 2013). This lack of participation poses significant challenges for research recruitment, which may create further gaps in health disparities already present in this underserved population (O'Connor 2013, Buseh et al 2013, and Mayer-Davis et al 2009). East African communities in King County comprise people from diverse origins. While they share some things in common, combining them into one group may be too overreaching and may ignore important nuances that differentially impact participation in clinical research. This study explored the differences and similarities in perceptions towards clinical research and Type 1 diabetes (T1D) in these communities.

For the last three decades many African migrants fled from civil war, political repression

and violence in their homelands and resettled in areas in the Northwest including King County, with including an increasing numbers the from East Africa (Boise, L et al, 2013). There are two ways most African migrants arrived in King County: 1) by applying for a diversity visa, and 2) applying for refugee status (Ethnomed, 2014). Most of the East African migrants in King County arrive as refugee status recipients (Ethno med, 2014). Even though most refugees receive some governmental assistance, including some financial and health coverage, African migrant refugees still face other health disparity challenges including barriers to accessing care, low educational attainment, lack of English fluency and difficulties with acculturation, which might exacerbate and further health disparities (Boise, L et al, 2013).

East African communities in Seattle/King County are comprised largely of three nationalities: Ethiopian, Eritrean, and Somali.

Ethiopia is one of the oldest countries in the world and it is the world's 14<sup>th</sup> most populous nation. (HistoryLink.org, 2010) Ethiopia has diversities of ethnicities and religious faiths. Roughly 46% of Ethiopians are Ethiopian Orthodox Christians, while 43% are Muslim (HistoryLink.org, 2010). Ethiopian-born immigrants account for 0.5 percent of the U.S foreign-born population and about 12% (150,000) of African migrants in the U.S (U.S. census, 2010). Even though roughly 70% of the Ethiopian immigrant population in the U.S. is heavily clustered around the Washington, DC area, a good portion of the population resides in other U.S. cities including Seattle (Rockefeller Foundation-Aspen Institute Diaspora Program, 2014). The first groups of Ethiopians in King County were students arriving in Seattle in the late 1960s and the early 1970s (HistoryLink.org, 2010). The majority of these students stayed in Seattle after their home

country's regime changed. Over time due to increased instability in Ethiopia, they sponsored their families to join them, resulting in the growth of the Ethiopian community in King County (HistoryLink.org, 2010). The total Ethiopian population in the greater Seattle area is estimated at between 6,000 and 7,000 (U.S. census, 2010). Ethiopians in the U.S have high educational attainment in general with an estimated 54% of Ethiopians having one or more years of college (Gambino et al, 2008-2012). However, Ethiopians settling in Seattle come from rural areas and often have little or no formal education when compared to Ethiopians residing in other states (EthnoMed, 2014).

According to the 2010 U.S census, Eritreans accounted for about 3% (35,000) of all Africans migrants in the U.S. In 2010 there were roughly 5,000 to 6,000 Eritreans living in the greater Seattle area, and this number continues to grow (U.S. census, 2010). The majority of Eritreans are Christian Orthodox and, like their Ethiopian counterparts, most come from rural areas (EthnoMed, 2014). They have a lower educational attainment than Ethiopians, with about 23% of Eritreans in the U.S. having one or more years of college (Gambino et al, 2008-2012). A small number of Eritreans arrived in Seattle around the same time as Ethiopians, during the 1960s and 1970s, as students on scholarships. In the late 1970s, the first Eritrean refugees began arriving after a U.S. policy change towards African refugees during the Carter Administration (HistoryLink.org 2014). In the early 1980s many Eritrean families that sought refuge in the Sudan were resettled to Seattle through refugee resettlement programs (HistoryLink.org 2014).

Somalis comprise the largest East African immigrant population in King County. The 2010 U.S census estimated that about 76,000 individuals of Somali origin are living in the U.S. and they account for 6% of all African migrants in the U.S. The number of the

Somalis living in King County is estimated to be as high as 13,000 (U.S. Census, 2010). The well-documented civil war that started in 1991 left many Somalis stateless after experiencing mass violence, bloodshed, and human rights abuses in their own country. More than 2 million Somalis have sought refuge in neighboring countries such as Kenya, Ethiopia, and Yemen, while over half a million Somali refugees migrated to Europe, Australia, New Zealand, and North America (Warfa, 2014). The Somali war led to the displacement of many people and forced migration, which contributed to increase in the Somali population in the U.S and in King County. The majority of Somalis who live in King County came as refugees as a result of that catastrophic civil war (EthnoMed, 2014). Additionally, Somalis like Eritreans, have low levels of educational attainment with only 27% Somalis in U.S. having first year of college and beyond (Gambino et al, 2008-2012).

Nearly all Somalis are Sunni Muslims (EthnoMed, 2014). The majority of Somalis in King County follow strict Islamic guidelines closely. Their Muslim faith may contribute with challenges with integration further when compared to the previous two East African communities. The Muslim faith requires individuals to pray five times a day, which is very difficult to maintain in non-Muslim countries. Also, Muslims have strict dietary requirements surrounding how meat is butchered (halal) making it difficult to shop in regular American grocery stores. Additionally, women in Islam are required to cover their hair, wear a hijab, and dress modestly making them more distinct from other immigrants. Other challenges include some forms of discriminations some Muslims face after September 2011 terrorist attacks (HistoryLink.org 2014).

There is very little literature outlining the factors associated with low clinical research participation among East African immigrants (O’Conner, 2013). The limited available research describes barriers that affect all African immigrants including a deep mistrust towards Western researchers, and some community leaders acting as buffers and gatekeepers between their community and researchers in order to shield their community from any perceived harm or other interactions from outsiders, including researchers (Buseh et al, 2013). These barriers might cause many western researchers to hesitate to conduct research in these communities (Buseh et al, 2013). The limited available research indicates that mistrust among African migrant gatekeepers stems from colonial legacies and research abuses in their homeland, where research was often conducted without following ethical guidelines and practices were in clear violations of the Helsinki Declaration. (Buseh et al 2013) The goal of this project was to explore the perceived barriers and motivators to participation in clinical research by East African immigrants in King County. This paper specifically aims to identify similarities and differences across three East African communities (Ethiopian, Eritrean and Somali) regarding participation in clinical research, exploring the themes of religion, culture, and trust.

## **METHODOLOGY:**

### **Recruitment**

Given the limited data available to guide researchers in recruitment of East African communities in clinical research, we used key informant interviews and focus group discussions. Key informants were employed at or worked with the following health and social services related community organizations: East African Community Services, Horn of Africa Community Services, Somalia Community Center of Seattle, Eritrean

Community Center, Tigray Community Association, Refugee Women's Alliance, and Harborview Medical Clinic. Purposeful sampling was used to recruit the focus group participants, because of the common characteristics shared by this population (Sandelowski, 1995). One member of the research team is from Somalia and he recruited all participants utilizing previous connections and calling and meeting community leaders for the three-targeted communities, to identify participants that met the inclusion criteria, and who were willing to participate in this study. Participants received and signed a written copy of the consent form after reviewing it with the principal investigator before the key informant interviews and focus group discussion began. A gift card of \$25 was distributed to all the participants at the end of the interview. Institutional Review Board approval to conduct this research was received by the University of Washington prior to conducting any study activities.

### **Participant Characteristics:**

Participants (N=22) were East African individuals living in King County, five male and 17 female adults aged 18 and older. There were two independent groups of participants: key informants (N=6) and focus group participants (N=16). Key informant participants were defined and identified as individuals with considerable experience and expertise in navigating the US healthcare system. There were four female and two male key informants. One key informant had a masters-prepared in public health, one was a social services professional, two were public health graduate students, whilst the remaining two were long-time community health workers and medical interpreters. Eligibility criteria for key informants included: (1) aged 18 years and older; (2) a member of one of the three target East African communities; (3) employment in a health care or social service

profession for several years; (4) work and/or involvement with organizations that work with the target populations. Focus group participants included 13 females and three males, from targeted communities (Eritrean (n=5), Ethiopian (n=5), Somali) (n=6) who were parents of youth under 18 years old without a diagnosis of type 1 diabetes (to avoid research fatigue in targeted future studies).

### **Data Collection**

The key informant interviews and 3 focus group discussions were held with members of the East African Community residing in King County, Washington to determine the broader perceptions of participation in clinical research and perceptions of research specific to type 1 diabetes. All key informant interviews and focus group discussions were held in a location that was convenient for the participants. This included the workplace of the key informants, and for the focus groups, an Eritrean restaurant in South Seattle, an Ethiopian Youth Multimedia Center at Seattle's Central District, and a Somali Youth Center in South Seattle.

The principal investigator of the parent study developed interview guides that included introduction questions exploring participant knowledge and understanding of clinical research in general and related to T1D in particular. The key informant interviews were followed by three focus group interviews for the three-targeted communities to check the accuracy of key informant perceptions with other lay community members. All key informant interviews and focus group discussions were audio recorded and conducted in English.

All key informant interviews and focus group discussions were facilitated by the Somali research team member with the principal investigator in attendance to observe the interviews and focus group discussions. The moderator guides for the individual and group interviews were divided into the following topic areas: key informant guides consisted of introductory questions discussing participants' role in the community, the organizations they work or worked in, and their experiences regarding Seattle Children's Hospital (if any) (See Appendix 1 and 2 introduction and Questionnaire guide for specific questions). Key informants were asked general questions relating their perception of clinical research to briefly assess participant knowledge of the topic. This guide was intended to facilitate an easy transition from the introduction to the key study questions: the perceived barriers and motivators to clinical research participation. The discussions were semi-structured and consisted of open-ended questions followed by a series of probes for each topic area. For example, in the section on general perceptions to clinical research participants were asked, "Have any of you ever participated or known someone who has participated in clinical research?" (Probes solicited specifics around personal experience, family members, friends, or others). The focus groups also followed similar techniques, beginning with an introduction, then asking the participants the length of time they had resided in the U.S., followed by questions about their perceptions and experiences about Seattle Children's Hospital, and their understanding of clinical research. These questions were followed by specific questions to elicit participants' perceived barriers and motivators for participation to clinical research.

**Data analysis:**

A digital audio recording was professionally transcribed after completion of the key

informant interviews and focus groups discussions. The two researchers who were present during key informant interviews and focus group discussions also conducted the analysis. They listened to the audio recording prior to coding and reviewed the accuracy of the transcripts. No inaccuracies were found in either the key informant interviews or the focus group discussion transcripts. The principal investigator of the parent study developed a codebook using concepts from the interview guide, such as understanding about clinical research, participation of clinical research, barriers and motivators to participation to clinical research in general, as well as those pertaining to culture, religion and trust the latter being the specific focus of this analysis.

A thematic analysis (Ryan, Bernard, 2010) of the transcribed interviews for the key informants and focus groups was performed. This process involves the iterative process of coding the narratives into common themes, by reading and re-reading the whole text to become familiar with the overall content of data. The next step involved using the qualitative analytic software program, ATLAS.ti, to organize the text into themes by assigning codes to specific sections of the text. For this step, the transcripts were analyzed line by line and assigned a code from the a priori list. This analysis is based on those sections of the transcripts associated with the codes for barriers and motivators relating to the culture, religion and trust. There are many different techniques to employ in order to find common themes. This study used two major theme techniques, repetitions, and identification of similarities and differences (Ryan, Bernard, 2010). Repetition is easy to recognize from the interview(s) (Ryan, Bernard, 2010). This process involves grouping together all excerpts about perceived barriers and motivators relating

to culture, religion, and trust. We then re-read these excerpts to identify similarities and differences in the perceptions between the three communities (Ryan, Bernard, 2010). Patterns and themes were examined in all key informant interviews and focus group sessions to identify any repeating differences and similarities that might exist in the three communities. After this initial coding, we created subthemes of similarities and differences for culture, religion, and trust within the three groups to capture the nuances in how the different groups viewed culture, religion and trust.

### **Results:**

The data revealed 3 themes related to barriers and 2 themes related to motivators to clinical participation among these three East African communities living in Seattle and King County (See Table 1). Barriers identified by participants fell into three themes: Cultural, Religion and Trust. With respect to cultural barriers to clinical research participation, two subthemes were identified: (1) lack of understanding of clinical research; and (2) stigma. Participants indicated that there exists a general lack of understanding of clinical research among members in all three groups. Stigma was identified as a barrier among Eritrean and Ethiopian participants but not Somali participants. Religion was also identified as a barrier to clinical research participation. All groups mentioned the role and importance of religious healing and practices in addressing health issues and as an alternative to seeking medical help in hospitals and clinics, where much of the clinical research is done. Trust issues arose as another barrier to clinical research participation but perceptions of how trust created barriers varied widely among the three groups. Three different subthemes regarding trust as a barrier emerged and included: (1) reliance on other community members to broker relationships

in the Eritrean community; (2) a lack of understanding with regard to the benefits of clinical research among Ethiopian participants; and (3) a focus on past mistreatment and negative experiences of African Americans in research and in receiving substandard health care services in the Somali community.

Religion and Trust themes emerged as motivators to participation in clinical research across the three groups. Participants across the three communities agreed that the development of collaborations with religious leaders (religion) and efforts to reach out to the East African community to explain the benefits of clinical research (trust) would be strong motivators for participation. These themes are elaborated upon below with the inclusion of exemplar quotes.

**TABLE 1: THEMES**

Similarities and Differences between East African community members regarding barriers and motivations to participation in research		
	<b>Barriers</b>	<b>Motivators</b>
<b>Similarities</b>	<ul style="list-style-type: none"> <li>• <b>Cultural Subthemes</b> <ul style="list-style-type: none"> <li>a) Lack of understanding of clinical research (All)</li> <li>b) Stigma (Eritrean, Ethiopian)</li> </ul> </li> <li>• <b>Religion Subthemes</b> <ul style="list-style-type: none"> <li>a) Religious healing and practices (All)</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• <b>Religion Subthemes</b> <ul style="list-style-type: none"> <li>a) Collaboration with Religious leaders. (All)</li> </ul> </li> <li>• <b>Trust Subthemes</b> <ul style="list-style-type: none"> <li>a) Reaching East African Community and explaining the benefit of clinical research. (All)</li> </ul> </li> </ul>
<b>Differences</b>	<ul style="list-style-type: none"> <li>• <b>Trust Subthemes</b> <ul style="list-style-type: none"> <li>a) Reliance on other community members (Eritrean)</li> <li>b) Lack of understanding of the benefits of clinical research (Ethiopian)</li> <li>c) Previous mistreatment of African Americans (Somalis)</li> </ul> </li> </ul>	

## **BARRIERS: SIMILARITIES ACROSS GROUPS**

### **I. CULTURE**

Participants in all three focus groups and key informants shared similar concerns that their culture's lack of experience and knowledge about clinical research made it hard for them to participate in clinical research. Participants considered not having previous experience and knowledge about research as a cultural barrier, rather than a knowledge-based barrier. Also participants from the three communities remarked that their community does not have the experiences and the understanding of the benefits of clinical research.

#### ***A. Lack of knowledge about clinical research***

**Eritrean Community:** When Eritrean participants were asked if culture was a barrier to clinical research, they cited a few reasons including not having the background knowledge and experience to inform research participation, as well as limited or no understanding of the benefits of clinical research. One key informant noted, *“Not a lot of them have a whole lot of knowing about what research is and what they can get out of research.”*

Also an Eritrean focus group member remarked that lack of understanding about the benefits of clinical research was the reason Eritrean communities were not participating clinical research. One participant commented, *“Because they don't understand what the benefit of research is it's really hard for them to make an appointment, to come to the interview, to do the interview or to talk about it. Sometimes, they don't even want to talk about the issue that you're doing research on. It has to be somehow, you have to really*

*relate to do it person to person. Why you're doing this kind of research and how it's going to benefit them, what the outcome is.”*

Other factors that were discussed included conflicts between clinical research values and Eritrean parents' beliefs and values. As one focus group participant explained, *“Well, just speaking in particular about my community, I know oftentimes they don't – they would not approve of somebody participating in something like that because it's not something that is culturally appropriate. I also think that the cultural values and ties that East Africans hold may not be something that's aligned with clinical practices. And so I think it's cultural.”* This was an important highlight of some of social norms that exist within the Eritrean culture that may contribute to the lack of participation. Since participating in studies was neither common nor experienced by the Eritrean community both in the US and back home, participation in such studies are considered to be outside the social norm and defined as culturally inappropriate.

**Ethiopian Community:** Ethiopian participants reported that growing up in a culture with limited knowledge and experience with clinical research might hinder their understanding of, participation in and benefiting from clinical research. As one focus group participant stated, *“Cultural it is because we are not growing up in this society so we don't know the benefit of research so it's just they don't know what's going to happen. And maybe it would be cultural more of the knowledge I guess how they affect the cultural part.”*

Ethiopian key informant participants described how their culture was not familiar with the word 'research'. The use of the word research might sometimes even hold a different meaning, as one key informant participant remarked, *“So the word research itself has no really particular meaning in, for example, in my native Oromo language. It means*

*laboratory. If you said research is synonymous with lab. So if you talk about lab, then we're talking about you know, somebody in the lab, drawing blood, something like that. That's the perception, that's the picture that comes up."*

**Somali community:** Somali participants repeated what Eritrean and Ethiopian communities shared about their communities' lack of knowledge and experience in clinical research. Both key informant and focus group participants stated that the majority of their community have never participated or engaged in clinical research. *"The culture this East African community don't have that kind of experience for participating clinical research like the dominant culture, specially Caucasian American who knows what clinical research is and willing to participle clinical research."*

Due to the lack of previous experience, knowledge and exposure to clinical research, Somali focus group participants in this study agreed that they sometimes have negative perceptions about who benefits from clinical research. *"And sometimes people have wrong ideas about research, that it's benefiting companies or corporations or who's ever doing it. And it's not for the good of the people or the community."*

Somali participants explained that cultural barriers also impacted the interactions between the community and the health care system in general. They explained that most Somali's seek care only when it is necessary, even here in US when individuals have access to healthcare. *"I think always culture might be a barrier, and the reason I'm saying that is you know, like where we came from back home, we only go to the doctor when we're very sick, there's little kids and pregnant women, they might have health care system, but people, even though they have a doctor they can go, still they only go when they're sick."*

This behavior of seeking care only when is needed might limit the community's opportunity to be part of recruitment and participation for research. In many cases in clinical research occurs in the medical care setting. Due to the lack of contact or limited contact with potential participants from this setting, opportunities to recruit members from the Somali community are diminished. The effect of this widens the access for Somalis to gain more exposure in research participation and continuing the cycle of non-participation.

### *B. Stigma*

Both Eritrean and Ethiopian participants shared how stigmatization of health conditions in their culture impedes access to care and participation in research. Eritrean and Ethiopian cultures are traditionally collective societies that emphasize on the importance of community cohesiveness and interdependence. Members of these two communities argued that stigma (fear of being labeled and ostracized from the community) played a significant role in members not disclosing medical conditions publically, which would include research settings where full disclosure is often a requirement. This is particularly the case in focus groups where other members of the community are also present and putting them at risk of exposure which may change their interactions within the community. Therefore, they are reluctant to participate for fear that others would become aware of health conditions and be ostracized from their community. Stigma as a barrier to research participation was not raised by the Somali community.

**Eritrean Community:** Another theme that arose among Eritrean participants was stigma. They explained the need for individuals to keep his/her sickness to themselves due to the fear of stigmatization. It is difficult for members of the community to disclose

their health status and participate in clinical research when they have fear their information might be exposed. As one focus group participant shared *“In our culture, as you know, we don't really talk about a lot of issues. Even if you have some kind of sickness you don't want to share it with others. You want to keep it to yourself.”* Eritrean focus group participants discussed the shamefulness that comes with sharing personal health issues with others, again highlighting the challenges community face for disclosing their health conditions when ask to participate clinical research. *“That's the culture that we come from. It's really hard for a person from East Africa to sit down and talk about being sick or I have diabetes. They hide it. They get shameful, they don't tell the family. They hide it. So culture is a barrier.”*

Participants offered reasons why community members do not share their health status with other members in the community even when they are in US. Many stated that it is difficult to change the norms and customs with which they have grown up for years. One participant responded, *“If you're born, or like you know when you came young age here, like easily you can get it to change, but when I came you know almost 30 or 20 something, you cannot tell what's going on with you. You hide it. We have that problem.”* Focus group participants indicated that they are slowly learning to open up and share information about their health status with others. *“You're not open to tell, but you can learn, and learn, and learn.”*

**Ethiopian Community:** Ethiopian focus group participants also stated that several barriers to open discussion about health issues exist within their culture and often-cultural norms prevent individuals from sharing their problems with other community members, this might also impact when member of the community are approach to participate

research. *“You know as a culture-we do hide [sickness] when we just I know one way but it depends on the other person. There is no open discussion and that’s problem”*. One key informant participant acknowledged that the Ethiopian community hides sickness because of the high stigma associated with being ill, *“The communities hide everything. There’s a high stigma. If you’re sick, people will think you have something. Oh, I don’t know what happened to you.”*

Several focus group participants acknowledged the need to change, learn, and share with one another and adjust to the norms regarding open communication of illness present in their new adopted home. *“Our people must open up to discuss things and learn how to agree disagree just like way of democracy here in America, we must learn from one another. We have to open up here and discuss things. But we have to learn one another. I have to learn from her, from him-you know just everybody.”*

## **II. RELIGION:**

Across the three East African groups, participants agreed religion itself may not be the barrier to participation but the culture within which religion is practiced may cause the barrier. Although the three communities have distinct religious beliefs and practices participants agreed that the importance of religion in the community and the ways in which it is practiced may create barriers to clinical research participation as well as participation in the larger health care system. Participants cited two reasons that might exacerbate the barriers: 1) Religious healing practices; and 2) specific religious beliefs that exist due to long-term practices within families or groups which are *not* in fact required of the religion but are *believed* to be required due to ongoing practices.

### ***A. Religious healing practices***

**Eritrean Community:** Eritrean participants believe the familiarity and reliance on established religious practices might be the cause of the barrier; the community has used religious treatment for illnesses for so long that community members are more likely to explore that option first before seeking medical care, thus, they might never come in contact with people who could discuss research studies that might be of interest to them. The majority of Eritreans living in Seattle/King County are Christian Orthodox and follow strict orthodox practices, especially elders. When asked the question if religion might present barriers to clinical research, most Eritrean participants explained that it might be a barrier due to the important role of religion in decision-making, which makes the community more influenced by religion. This often results in the exploration of faith-based remedies before seeking medical care. As one key informant participant explained, *“They’re [Eritrean Community] more reliant on their religion and more tied to that, and more likely to explore those options versus going to a hospital or something like that.”* Furthermore, Eritrean focus group participants perceived that some people from the Christian faith might want to go to the church first, attempt healing through the use of holy water, or perform prayers and other religion-based methods of healing before seeking medical care. Others sought to combine medication with prayers or holy water; because of this practice seeking religious healing first, some members in the Eritrean community might never get the opportunity to interact with health care system and reduce their chance to participate research. *“It could be a barrier. Some people would rather go to church. I’m a Christian so my belief is first you have to go to church and get healed by holy water or by doing prayers and different method of religion before you go to the doctor and get medication. Nowadays maybe 50 percent of the population*

*medication comes second but they like to do it through the prayers and through the holy water.”*

**Ethiopian Community:** Even though the Ethiopian community is evenly split between Christian and Muslims, participants shared similar views about how religion might impact participation in research because religious practices keep people out of the health care system where they are most likely to learn about research studies. Ethiopian participants perceived that religion itself was not a barrier, but it is how individuals make decisions. Also, the participants view research as part of the larger health care system and many of their perceptions regarding research are rooted in their beliefs and attitudes about the health care system. As the focus group participants stated *“Some one may refuse to participate or get medication for diabetic but go to church thinking is it religion that will cure.”* In other words, one person may prefer to seek treatment through prayer, whilst another may want to use traditional western medicine, and others may see the benefits of participating in research. Therefore, implying that individuals that prefer religious interventions are more likely to decline medical interventions and research participation.

Ethiopian focus groups participants stated that prayer was the only option available to many when they or family member are sick as often-western medical treatments or clinical research was not available to them. One focus group participant shared that when she was young, whenever she got a headache she would pray. *“I mean I’m a child myself, was a child but still, but I mean that’s what I used to do. I get a headache or something than I would pray. In our community we are sick we pray. We don’t think insulin-giving insulin but holy water and prayers. And so I think it just kind of interacting with religion*

*and medicine so.*” Also focus groups participants discussed the importance of creating a culture where western medicine and religion coexist, highlighting the importance of their religion but also emphasized the need of medical intervention including participation of research. *“[There needs to be] more education of medicine, how important it is. It’s important to have religion but also being aware of medicine here especially might help.”* Furthermore, Ethiopian participants perceived that as older generations were more likely to stick with the traditional religious views this might influence the younger generation to follow in their footsteps. *“I mean the usually follow the parents and so if a diabetic parent is telling their child, “Oh I pray to god and god is going to cure me. I’m not going to take my insulin.” Of course they might be following that too.”* Again this above quote demonstrates how participants are lumped together clinical research and health care system in general. This may mean if the older generation does not accept a mainstream intervention and participation of clinical research the younger generation might not accept it either.

**Somali Community:** The majority of Somalis are Muslim but nevertheless Somali participants held similar view points as the Eritrean and Ethiopian participants stating that religion is not the barrier, however barriers occurred based on individual understanding about the role of religion. Somali participants agree Islam religion encourages the individuals to seek care, and participate any activities that are beneficial to their health. They alluded to religious barriers arising, when practicing person cannot separate or distinguish the differences between religion and cultural practices. Also Somali participants cautioned it is not the religion causing the barriers but the practicing individuals’ interpretation for the religion. They all agree religion might not be the barrier

to research participation unless is it harm or invasive to the subject. Focus group participants stated that religion supports clinical research if it is beneficial to the person or the wider community. *“If explained well the benefit I don’t think religion will contradict to research.”* The focus group participants continue, *“I don't think religion gets in the way, but people get in the way. It's the interpretation of people. Because if we say religion gets in the way, we are accusing religion, because these are individuals, and it's their understand .”*

Somali focus group participants in the study identified that there were difficulties distinguishing between religion and culture. *“I want to be careful when I say this, because religion, especially in the Somali culture, becomes a cult it’s like we our culture revolves around religion so much.”*

Somali participants expressed the belief that religion can never be a barrier if the individual in question had full knowledge or understanding about the religion. They argued that sometimes some Muslims do not know what is obligatory in their religion, due to the lack of understanding about their religion, which might result in the person believing that participating in certain activities, in this case clinical research is disobeying Allah. *“Some people they might claim they know the religion but the way they practice in the different. No, that's their lack of information from the medical side and from the religion side.”*

The Somali focus group participants believed that the Muslim faith held many answers for them, which benefited the health of individuals as a whole. However, they argued that average-practicing Muslims may not know all the details of the faith and only good scholars have the greatest knowledge, *“There's so many answers there in the Quran and*

*the faith itself, that it's actually very beneficial to our health as a whole, but we are not really know– it takes a good scholar to get that information out.”*

## **BARRIERS: DIFFERENCES ACROSS GROUPS**

### **I. TRUST:**

Trust was the only theme that emerged as a barrier where participants in the three groups differed about how and why trust might be a barrier to clinical research. All agree that trust barriers are common to their communities, but they differ in the source of the mistrust. Eritrean community participants believe that their community relies on the experiences of the fellow community members and bad experiences are shared by word-of-mouth and may create barriers to participation. They also shared that their community was traumatized by previous harsh experiences in their homeland. The Ethiopian community members shared that members of their community did not understand or could not assess what clinical research entailed, its purpose, its function, or benefit; therefore they were reluctant to be involved or trust the intentions of researchers or health care professionals.

Somali participants expressed their suspicion as a product of previous mistreatment by western researchers of minority communities, particularly African Americans and African natives. Participants explained their worries about getting fair treatment based on witnessing that many African Americans who have been in the U.S. long before them continue to experience disparities in health and health care.

#### **The Eritrean Community**

##### ***A. Relying other community members***

Eritrean participants shared a few different reasons about why trust might be a barrier to clinical research for East African communities. They discussed how community members influence each other through bad or good experiences, sharing that if one member of the community had a bad experience interacting with the healthcare system they are likely to influence others by telling them about that experience. This may prevent others from participating and/or seeking care at a particular health care setting. One key informant participant remarked, *“So the way I see it sometimes is like if one member of the community has had bad experience with the healthcare system, they often have an influence over what happens with other members in the community, so if one person had a bad experience, they’re more likely to influence how other people perceive that healthcare system. So if one person got, I don’t know, wasn’t valued or didn’t feel like they could get the support that they needed or services that they needed, they’re more likely to tell somebody don’t do this or they deter them from participating or even going to that healthcare system.”* The important role of community experiences in research was highlighted as members of the Eritrean community were heavily influenced by how members of their community feel towards research and base decisions on the previous experience of their members.

Additionally, research targeted towards individual health did not appeal as much to this community as they from a collective society where the benefits for the community are a more desirable outcome. As one key informant articulated, *“I think oftentimes when we talk about health we tend to talk about health as an individual health, and we’re not talking about community health. And so I think because we come from a very community oriented background, I think we always have to go back to the things that really resonate*

*with people, and I think oftentimes that's what resonates with people when we're talking about, okay, this is something that you're doing for your community.*" This suggests that Eritrean participants may be more likely to participate in research if research outcomes would benefit for the whole community, rather than individual benefits.

### ***B. Previous mistreatment***

Eritreans also shared that their community is traumatized from previous harsh experiences in their homeland. Other reasons Eritrean participants' identified as creating mistrust include previous mistreatment, adversity and deceptions suffered by the Eritrean community in particular and the immigrant refugee population in general at the hands of their former governments. The overall feeling was that researchers need to invest time and develop trust in the community. As one focus group participant noted, *"Like I said earlier, the immigrant refugee people come through so much hardship and they've been betrayed by their own country, the government, by so many. It takes time to develop trust between the researcher and the community."*

Due to previous mistreatment experienced by the Eritrean community, Eritreans preferred someone that they are familiar with to conduct research in their community. A key informant participant shared, *"They have to do it with someone familiar, someone they trust already, and someone they knew before the research day. If you just go there without being familiar people might not trust you. Why do you want to get my idea? Why do you want to get my identity? Anything that they have to sign they will question it. That's a big issue too."* In many cases since this is not possible, Eritreans are apprehensive when participating in research when someone unfamiliar is conducting the research or recruiting for the research. This was also present for the focus group

participants. When asked to go into more detail they concluded that they are more likely to trust someone they had previous experiences. This was especially the case when participating clinical research. *“Because all people are not the same, some people are trustworthy, some people are not, yes, it hard to tell, you need to know the person.”* This again highlights the tight knit culture of Eritreans, which places important emphasis in established relationships for trust to occur.

### ***C. Feeling that they are not a priority***

Eritrean focus group participants believed they are not a priority in clinical research and the health care system in general because of being black. As one key informant participant remarked, *“I think blacks have a barrier where they’ve often felt like the research or even when they’re getting healthcare services, that they’re not the priority in that and that their needs are not being met.”* This sentiment was shared by another key informant participant, *“ I think oftentimes whether it’s something that has happened in our own community or blacks general, oftentimes they’re not necessarily the reasons why things aren’t being recommended to them.”* Therefore, it was perceived that that there were other motives behind research that which were not designed to meet the particular needs of the community, nor to serve the best interests of the community. Eritrean participants also felt that even when members of their community do get the opportunity to participate in research they never see the results and question the benefits of participating. As one participant put it, *“Even the people who have some kind of research experience don't see the outcome most of the time. They always question, I did this research but what happened? What is the benefit?”*

## **The Ethiopian Community**

### ***A. Lack of understanding of the benefits of clinical research***

**Ethiopian Community:** Ethiopian participants acknowledged lack of knowledge about the benefit of research might create the mistrust. As one focus group participant remarked, “ *It could be a lack of trust because they don’t know what the benefit*” this was also true for key informants as one key informant repeated. “*The lack of understanding of the benefit of research itself plays a really big role in this community.*”

Another reason Ethiopian community participants think trust might be a barrier is, when parents do not know what they are getting into in health care or research. This often leads to parent avoidance of participation in research or the larger health care establishment as a means to avoid mistreatment of their children. For East African parents, their first order is to protect their children from exploitation. They will ask what it is the risk involves for exposing my child in clinical research, which are natural inclination feeling, parents and community in general always protect their young. “*The community’s first thing is you know, what is this about? What are you doing to my child? You know, this is again across the world. You know, even the people who are educated want to know what do you want to do to my child?*”

Also, focus group participants shared that if community members had knowledge or understood what the research is about, they would be more interested in participating. One participant added, “*So it comes down to education, being aware, awareness that could interest you if you don’t know anything about it why would I want to.*” Here the participant emphasized on the need for participants to understand the importance of research and how participation may benefit others. This demonstrated that it was

important for participants to receive more knowledge about research, provide transparency for the purpose of the study, and give participants more information about how these findings will be used, in order to increase community buy-in.

## **The Somali Community**

### ***A. Previous mistreatment of African Americans***

Past exploitation was one of the reasons Somali participants in this study believed there is mistrust of the health care system in the community. East African communities are associated with and a part of the larger African American community here in the US, and share beliefs with other African-Americans, Somalis felt that exploitation and racism may affect treatment. As one Somali focus group participants noted, *“Even African-Americans in my perception is they are low in participating this kind of – well, even organ donation, and all those things are really because people feel they are not involved or they victimize themselves as they believe that.”*

Because of what happened to African Americans in this country in the past many Somali focus group participants believe trusting researchers is huge consideration in order for them to participate in clinical research, they explained their mistrust rooted from what they learn from history, how researchers treated African Americans which they relate closely. They shared the reservation for getting fair treatment. *“They to take care of me? Knowing that there was an African-American person who was living here before that didn’t get that treatment. What makes them for me to help me? So you know, the damage has been done for the healthcare field already”*. That sentiment was also shared with key informant members, as one key informant explained, *“Some research that it's intended to find the problem, while some of them are exploiting, you know, people. And depending*

*on what aspect of clinical study that you talk about, with the history, you know, there have been clinical studies that have been using people as a medical tool to find solution on people.”*

Some focus group participant shared the reason they might not want to participate clinical research, acknowledging the negative aspect of being experimental or labeling a guinea pig. *“I think it's the label that comes with it. You know? More of guinea pig. You know what I mean? I think that's why I personally haven't – this is my first one. I think I personally thought that it would be – I've only seen the negative side of it instead of the positive side of it, 'cause you get to be labeled whatever the research is.”*

Some Somali focus group participants believe an outsider researcher is better to conduct research in their community. They discussed how East African community centers cannot be trusted, for different reasons, on the other hand if outsider researcher is willing to come in to their community to conduct research shows the outsider researcher care and shows credibility for taking the initiatives. *“The community, a lot of times, doesn't really trust the community centers and their own East African representatives. So, when the research is outsider, it kind of shows some credibility, “Oh, this person is, yeah, coming from outside, probably will add something to us or give us knowledge. So, okay, we will participate with that person.”*

Other Somali focus group participants disagree citing if the outsider researcher don't know or understand the community's issues it might not work and produce opposite affect. *“If people don't really know the researcher, and if they don't think that outsider will understand their issues, because that person is an outsider, doesn't have enough knowledge about this community. So, both ways are from experience.”*

## **MOTIVATORS:**

### **I. RELIGION**

#### ***A. Collaboration with Religious leaders:***

All participants from the three East African communities agreed that the best way for researchers to reach and recruit East African communities to participate in clinical research is to work with religious leaders. They emphasize that the knowledge of religious leaders have about their respective faiths (Christianity and Islam) would help community members clarify any misunderstandings that may exist (e.g. what is permissible versus what is not), and decrease hesitations to participate due to religious obligations or perceived religious limitations. Also the religious leaders of east African communities are highly respected individuals and have a great deal of influence in their communities.

**Eritrean Community:** All Eritrean participants agreed that the church and mosques are the best avenues for researchers to begin engaging the community to recruit clinical research participants. They discussed the power and influence faith based organizations have in their community. As one key informants participant stated, *“Oh, yeah. I think researchers definitely have a number of avenues on how to reach community members. One is through the faith organizations. I think faith organizations have a really strong and powerful connection to the community, so I think oftentimes if you can go to those leaders and say, “Hey, we’re looking to do this type of thing.”*

Another focus groups participant believed that educating priests and Imams will help researchers reach larger member in the community, *“ Yeah, like if you go to the church*

*and educate the priest or the Imam first and tell them why you want to do this they will support you and notify the other people. You will have more acceptances.”*

**Ethiopian Community:** Ethiopian participants like Eritrean participants believe connecting the religious leader will help researchers overcome existing religious barriers and facilitate recruitment of the Ethiopian community into clinical research. As focus group participants remarked, *So if you get the leader, the Christian population here, they have kind of closeness to the system in some way. I don't know how. But they're very receptive in that sense. So if leaders are going to consent, then their flocks are going to definitely, you know, follow suit. So that's one way of getting there.”* Another participant added, *“Like if they communicate with the leader of the community and the religious leaders will announce this or talk about this. We're going to do this and this and it's going to help out the community and by doing the research we will figure out what causes it and then they will come up with a solution. This kind of talk will help coming from the community leaders.”*

The Ethiopian community in general has great respect for their religious leaders; researchers working and collaborating with religious leaders may result in reaching more community members, the focus group participants acknowledged *“Work with religious leaders because we have a culture listening to our priests or if you're Muslim or pastor. So if you guys work with religious leaders that would be big time. I mean if they know they can preach their followers so.”*

**Somali Community:** Somali participants agreed that research participation would benefit from researchers working with religious and community leaders to reach more participants and make their recruitment more effective. As key informant participant

commented, *“When you add the community services, and you add the religious institutions, they tend to bring a combination that is very effective, because these are the two main sources of information and resources from the community. They – the people would be more receptive to listen to this information if you used.”* Another focus group participant explained what happens when the outreach begins in the mosque, he stated, *“I have seen it before that some outreach happen in the mosque. You know? So when coming to the mosque, I think that's where people trust the most. You know? If that thing happen in the mosque that means it's proof. You know, you have a green light for doing it.”*

Somali participants concluded it is best for researchers to talk with religion scholars such as Imams when they are dealing with Muslim individuals, as focus group participant remarked, *“It is good, when they're dealing with the Muslims, to talk to the scholars and even, if possible, talk to the respective scholars of that certain – only every – as we know, we have different interpretation of the religion itself.”*

## ***II. Trust:***

### ***A. Reaching East African Community and explaining the benefit of clinical research:***

Even though three groups differ how trust might create a barrier to clinical research, they agree that there is a need for more education and outreach about clinical research and the potential benefits of participating in clinical research. The participants also repeated the importance that researchers to educate their community about clinical research.

**Eritrean Community:** Eritrean participants believe collaboration between researchers and community by having moderator or co-researcher from East African community will help bridge the trust barriers, as one key informants participant stated, *“I think community*

*members are more likely to be receptive again, and recognize maybe try to draw on the fact that, "Okay. This person is somebody who I recognize and so there's more trust in this person. I know who they are. I feel like their intent is always gonna be good."*

Another focus group participant stated having someone from the East African community as a research member might ease the community's anxiety about who to hold accountable if things do not go well. *"They feel they are related to that person and they trust that person. If something happened they have someone to be accountable to than any anybody else."*

**Ethiopian Community:** Also as other community members in this study, Ethiopian participants agree having someone from East African community as a part of researcher team might help facilitate trust. They cited the community seeing someone look like them might build trust. The focus group participants shared, *"Seeing their own people maybe person might help them ease up. Like when it's somebody from your own community who come and talk to you about this and make it easier and maybe there will be a trust there and even if not just building that relationship even if the researcher is outside of the community. Building that relationship is very important."*

Ethiopian participants also said having research member from community will play two major roles: 1) create community representation, which is very important to the East African youth, 2) knowledge about both the culture of research and of the East African community. *"Yeah for the young people yeah of course a representation is very important. A person who represent us in our community but in the meantime also who knows the system and how operates so teach better."*

**Somali Community:** All Somali participants in this study agreed the best way to conduct research in the community is having an outsider researcher and a co-researcher from an East African community doing research together. As one of the focus group participants stated, *“I believe that's the best way that a research could be done. I believe so. You know, a combination of both, yeah. And it will be successful, yes? Both persons are knowledgeable in doing the research and helping one another, understanding the inner and outer issues.”*

## **DISCUSSION:**

This study sought to understand the differences and similarities in perceived barriers and motivators to clinical research among three East African communities in King County, Washington. These three communities share commonalities, including geographical location, migration history, culture and religion (EthnoMed, 2014). The three major themes that were explored for this study are: (1) culture (2) religion, and (3) trust. This study finds East African communities have limited access to participating in and understanding of clinical research. Only three out of 22 participants in this study had ever been approached to participate in clinical research, which speaks to the lack of representation of this community in clinical research. This is consistent with the finding of previous research available, which emphasized the scarcity of available data for African migrants in general and East African in particular (Pavlish, et al, 2007). The stigma of disclosing health conditions discussed thus far in Eritrean and Ethiopian groups highlights some of the issues faced by those communities that might hinder the communities' willingness to participate in clinical research. Also Eritrean and Ethiopian

participants both key informants and focus groups expressed hope for the new generation of Eritrean and Ethiopians whom either are born in the U.S. or came as a young to the U.S. as they can easily adopt, change in comparison to their parents. Previous study supports this notion; the longer an immigrant resides in the U.S, their perception about health care system might change because of many factors including learning adequate language to communicate, better job prosperity which enables to adopt easily (Buseh et al, 2013)). What is also true, as many research in the past have explored, is that the longer an immigrant person stays in the West, the more their health deteriorates, reason being many might lost what researchers refers to as “immigrant health advantage” (Homer V et al, 2007). This theory is well understood with Latino population, further study might be need how this theory affects African migrants, which might have a different characteristics then Latino population in U.S.

Somali participants did not indicate stigma as a culture barrier. This does not mean Somali culture encourages or supports a community member sharing their health status with other community members. Previous study suggested Somali culture is prone to stigmatization especially of mental health conditions (Carroll et al, 2007, Palmer, 2007). Other available data discussed how stigma associated with mental illness prevents many Somalis from seeking treatment or assistance (EthnoMed, 2014). Other conditions that Somali community *might* associate with stigma include, HIV/AIDS and tuberculosis (EthnoMed, 2014). Participants for all three communities described the importance of using cultural traditions and participation in religious healing such as holy water and prayers treatments. This was also true from previous research that finds the some African migrants reliance for traditional treatment and religious healing ceremonies for both

protect against illness and treatments various forms of illness (Carroll et al, 2007). The practice of relying only the traditional way of healing might limit the interaction between communities and researchers, and hinder future recruit participants. Most participants for all three communities also acknowledged the importance for their religion in their life, where praying to God or Allah are practice that is so important to them. Other available research also came with that conclusion, suggest researchers should recognize and incorporate spiritual and religious foundations of health beliefs when recruiting African Migrants (Carroll, J, et al, 2007).

The trust barrier concern expressed for all three communities are rooted in three main reasons: 1) lack of knowledge about clinical research 2) previous treatments from African Americans and 3) not feeling important. Ethiopian community believes if members in the community cannot assess and understand the harm and benefit of clinical research it is hard for them to participate clinical research. This finding was also supported previous study by National Institute of Medicine Committee on Health Literacy almost 25 million, about 8.6 percent of the U.S. population, are identified as Limited English Proficiency (LEP), One of the most significant barriers faced by LEP patients and their families is lack of understanding how to access and receive care (Nielsen L et al, 2004). This lack of knowledge of accessing care might also be barriers to clinical research participation, by not knowing the availability and the benefit of clinical research. Individuals little or no knowledge about healthcare system are more unlikely to understand and participate clinical research.

Somali participates shared their reservations about getting fair treatments because past history for minority communities mistreatments for western researchers. This is

consistent with the wariness other African migrants community in U.S. expressed for previous research, referencing well-documented Tuskegee experiments to highlight the exploitation many African Americans have suffered in the name of research. (Buseh et al, 2013). Many African natives had bitter experiences and encounter with western exploitation including colonial legacy and western pharmaceutical interests conducting unethical research in their homeland (Buseh et al, 2013). The participants considered themselves as part of larger minority community in US, they believe acknowledging the past mistakes such as previous research misuse and addressing health disparity for minority community will help their community to overcome that mistrust. They also cited the negative label comes with clinical research such as guinea pig is discouraging the community to participate

Another barrier shared by Somali participants was the absence of practicing preventive care for Somali community, which was also supported by other findings about Somali patients who only seek healthcare when ill rather than using preventative care or services that available to them (Carroll et al, 2007). Delaying or avoiding accessing care limits the communities' interaction with health care providers; this can have multiple consequences while recruiting clinical research participants. First when someone seeks care at the point of need they might access that care through Emergency room, which is often crowded, and not a pleasant experience (DeVoe et al, 2003). Long emergency room waits and perceived inequitable delays in receiving care result in many community members lacking trust in the health care system in general, limiting or precluding their participation in future clinical research. Secondly, accessing care through a primary care provider has many benefits, including preventive care, early intervention and an established provider

relationship, which all contributes to higher satisfaction (DeVoe, et al, 2003), which might encourage individuals to participate clinical research.

Eritrean community participants believe that their community relies on the experiences of the fellow community members. If a perceived experience is a negative one, then the rest of the community might not seek care or engage that particular setting. Also, Eritrean participants believed that the reason their community are not participating in research is that they are not priority for the researchers because of being a black person in the U.S. There is overwhelming evidence, and a great body of literature that has demonstrated there is a significant level of mistrust towards the healthcare system in general and clinical research particular by minority communities in U.S. (Buseh et al, 2013) This issue was also presented in this study, therefore supporting other studies that address this issue directly. Additionally, this study found that some members in the Eritrean community might not want to participate in clinical research due to previous experiences with mistreatment by government agencies in their home countries before entering the US. Stressful refugee and immigrants experiences before reaching the U.S. have been well documented (Buseh et al, 2013, Boise et al, 2013), which may contribute to apprehensiveness to participate in research.

The three community participants also conveyed the importance that researchers build rapport and give people the confidence that the researchers are there to do something that is going to improve the community versus just something that is beneficial to researchers

## **LIMITATIONS**

All key informant interviews and focus groups were conducted in the English language due to budgeting issues associated with translation costs; this might have hindered some of participants abilities to express their beliefs and experiences in detail on complex topics such as culture, religion trust, and clinical research. A lack of English proficiency may have excluded many individuals from the targeted communities from participation. As a result it might affect the generalizability of this study. Further study may be needed for a health disparity comparison between limited English proficiency groups and those in the community with adequate English communications. Also, one Eritrean participant did not share her views even though she agreed and expressed understanding the nature of participation.

## **IMPLICATIONS FOR FUTURE RESEARCH AND PRACTICE**

To my knowledge this is the first study of its kind to compare the similarities and differences for perceived barriers and motivators among three East African communities. The generalizability of the finding would enhance future studies for East African community and African migrants in general. The growing number of African migrant populations in the United States, their changing health profiles, and needs demand the researchers and health care service providers to consider the epidemiologic and sociocultural needs of the African migrants (Homer V et al, 2011). In order to achieve the above goal, community based participatory research approach should be adopted to ensure that the community's voice is heard, including all the future research, program planning, implementation, evaluation and assessments for East African communities.

### **Recommendations for Researchers:**

1) Researchers should first take initiative to reach religious leaders and educate them on the benefits of research. Religion should not be a barrier if the community knows there are other options without abandoning their religion's obligation.

2) The researchers should acknowledge and respect religious treatment for illness. Combining both practices (religion and research) might produce positive results while recruiting participants to clinical research. This can be done through partnership between researchers and communities coming together and sharing each other's expertise and experiences.

3) Researchers should also emphasize and address the need of research members from East African communities, this can be done by actively reaching local high schools, undergraduate and graduate students from this community and all minority communities.

4) Taking into account the Somali community's cultural practice for seeking care when it is only emergently needed is another barrier researchers might need to address. This can be done with working members Somali health professional organizations such as Somalia Health Board (SHB) and primary care providers educate the members of Somali communities the importance and the benefit of preventive care.

5) Addressing stigma and incorporating stigma reduction programs for all future research approach to Ethiopian and Eritrean communities must be high priority to the researchers. Researchers must actively explore ways to reduce all of these identified barriers with help from and collaboration with the targeted community. Effectively engaging the East

African migrants communities and building trust with the East African community is necessary in order to prevent future persistence of health disparities.

**Conclusions:**

Findings of this study suggest East African communities in King County, Washington have more commonalities than differences relating to perceived barriers and motivators to participating clinical research. There was agreement across the three communities that culture, religion and trust impact their participation in and perceptions of clinical research, yet they differed in their beliefs about how barriers evolved. They all agree educating their community about the benefits of clinical research and future opportunities to participate in clinical research will lessen doubts about clinical research amongst East Africans.

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## **APPENDIX 1:**

### **Guide for Key Informants Interviews with East African Immigrant Community**

#### Introductions

- What is your role in the community? What organizations do you work with?
- What are your experience/thoughts regarding Seattle Children's Hospital?

#### Subject under study

- What is your understanding of type 1 diabetes (T1D)? Do you know anyone with T1D?
- Provide brief (5 min max) of T1D in EAI research to date
- Is this subject important? Why/why not?
- What is your understanding of clinical research? Have you or someone close to you ever been asked to participate in a research study?
  - Did you/they participate (why/why not?)
  - If yes, what was it like?

#### Perceptions of EAI Community Members

- What do you think would keep EAI youth from participating in research?
  - Prompts if needed:
    - \*linguistic
    - \*cultural
    - \*religious
    - \*lack of trust in researchers
    - \*lack of interest
    - \*too many requests to participate in research
    - \*obtaining informed consent
    - \*time requirements
    - \*costs to participants (i.e. lost wages)
- What do you think researchers can do to encourage EAI youth for clinical studies?
  - Prompts if needed:
    - \*location of study visit
    - \*knowing the researcher if outside the community
    - \*having a co-researcher/event moderator that is from the community
    - \*support of community/religious organization
    - \*financial compensation for time
    - \*other logistical support (transportation, child care, etc.)
  - If community meetings occurred, what is the best location? Time/day?

- Do you think that the barriers or motivators would be different for studies that involve genetic research?

#### Reporting of data

- What are your thoughts about how to share research results with the community?
  - Prompts if needed:
    - \*Mail?
    - \*Email?
    - \*Website?
    - \*A community event?

#### Next steps

- Are you interested in participating (as a community liaison, etc.) in future studies?
- Anything else?

#### Additional de-identified information, contact information to be collected via forms for each participant (if willing):

- Contact information (mail, email, phone)
- De-identified information only: country of origin, length of time in US, children (# and ages only), occupation, city of residence

## **APPENDIX 2:**

### **Guide for Focus Group Discussions with East African Immigrant Community**

### Introductions

- Where are you from? How long have you been in U.S.?
- What are your experience/thoughts regarding Seattle Children's Hospital?

### Subject under study

- What is your understanding of type 1 diabetes (T1D)? Do you know anyone with T1D?
- Provide brief (5 min max) of T1D in EAI research to date
- Is this subject important? Why/why not?
- What is your understanding of clinical research? Have you or someone close to you ever been asked to participate in a research study?
  - Did you/they participate (why/why not?)
  - If yes, what was it like?

### Perceptions of EAI Community Members

- What do you think would keep EAI youth from participating in research?
- Others community members have told us that \_\_\_\_\_ issues may prevent the East African community from participating in clinical research. Do you agree? Why/why not?

- \*linguistic
- \*cultural
- \*religious
- \*lack of trust in researchers
- \*lack of interest
- \*obtaining informed consent
- \*time requirements
- \*costs to participants (i.e. lost wages)

- What do you think researchers can do to encourage EAI youth for clinical studies?
- Others community members have told us that \_\_\_\_\_ might encourage EAI youth to participating in clinical research. Do you agree? Why/why not?
  - \*having study visits in the community
  - \*knowing the researcher if outside the community
  - \*having a co-researcher/event moderator that is from the community
  - \*having support of community/religious organization
  - \*providing financial compensation for time
  - \*providing other logistical support (transportation, child care, etc.)
- Do you think that the barriers or motivators would be different for studies that involve genetic research?

Reporting of data

- What are your thoughts about how to share research results with the community?
- If community meeting occurred, what is the best location? Time/date?

Next steps

- Are you interested in participating (as a community liaison, etc.) in future studies?
- Anything else?

Additional de-identified information, contact information to be collected via forms for each participant (if willing):

- Contact information (mail, email, phone)
- De-identified information only: country of origin, length of time in US, children (# and ages only), occupation, city of residence