

**IMPROVING TYPE 1 DIABETES MANAGEMENT: CONSIDERATIONS FOR A PEER  
SUPPORT NETWORK IN KIGALI, RWANDA**

by

**Emily C. Fitzpatrick**

BA, University of Richmond, 2013

Submitted to the Graduate Faculty of  
the Department of Epidemiology  
Graduate School of Public Health in partial fulfillment  
of the requirements for the degree of  
Master of Public Health

University of Pittsburgh

2019

UNIVERSITY OF PITTSBURGH  
GRADUATE SCHOOL OF PUBLIC HEALTH

This essay is submitted

by

Emily C. Fitzpatrick

on

April 28, 2019

and approved by

**Essay Advisor:**

Trevor J. Orchard, MBBCh, MMedSci, FAHA, FACE  
Distinguished Professor  
Department of Epidemiology  
Graduate School of Public Health  
University of Pittsburgh

**Essay Readers:**

Tina Costacou, PhD  
Associate Professor  
Department of Epidemiology  
Graduate School of Public Health  
University of Pittsburgh

Patricia I Documet, MD, DrPH  
Associate Professor  
Department of Behavioral and Community Health Sciences  
Graduate School of Public Health  
University of Pittsburgh

Copyright © by Emily C. Fitzpatrick

2019

**IMPROVING TYPE 1 DIABETES MANAGEMENT: CONSIDERATIONS FOR A  
PEER SUPPORT NETWORK IN KIGALI, RWANDA**

Emily C. Fitzpatrick, MPH

University of Pittsburgh, 2019

**ABSTRACT**

**Background:** As non-communicable diseases rise in low- and middle-income countries (LMICs), lack of access to care and social support become significant global health concerns. Collaborative work between the Life for a Child (LFAC) program and the Rwanda Diabetes Association (RDA) has improved access to treatment for youth with type 1 diabetes (T1D) in Rwanda. These youth, however, still face barriers in diabetes management. Youth with T1D need reliable methods for communicating problems which impair their continued treatment, and consistent social support from people who understand living with diabetes. Peer-support networks (PSN) are a way to address these social and clinical needs. Drawing on LFAC/RDA data and stakeholder insights, this project explores barriers youth face in diabetes management.

**Methods:** In June 2018, RDA data, previously collected between June 2009-February 2018, on 1,515 patients across the country were reviewed and analyzed to generate an updated LFAC/RDA registry as a baseline for planned future intensive follow up. Inclusion criteria were: seen in 2016/2017, aged <26yrs old, and received diabetes care primarily at the RDA. Youth were categorized as Kigali residents or out of area. Stakeholder interviews with the RDA and neighboring Tanzania Diabetes Youth Association (TDYA) were also conducted.

**Results:** Of 216 youth age eligible for the new registry, 9 (4.2%) had died and 26 (12%) were lost to follow-up leaving 181 registered youth, of whom 43 (24%) were non-Kigali residents.

Stakeholder interviews indicate that barriers for diabetes management include stigma, lack of emotional support, job insecurity, food insecurity, transportation costs and access to medicine. An outline for expanding currently available peer support programs was developed.

**Conclusion:** This preliminary analysis provides evidence for the need of a PSN in Kigali that could be scaled up nationally. One objective of the new registry is more rigorous follow up which can be facilitated through a PSN. Peer support would also encourage youth engagement, communication among peers and provide direct social support. The public health significance of this paper is considerable: youth with T1D face high mortality and morbidity with the rising epidemic of diabetes in LMICs and the need for meaningful innovative solutions is paramount.

## TABLE OF CONTENTS

<b>PREFACE.....</b>	<b>X</b>
<b>1.0 INTRODUCTION.....</b>	<b>1</b>
<b>1.1 DIABETES EPIDEMIOLOGY.....</b>	<b>2</b>
<b>1.2 TYPE 1 DIABETES MANAGEMENT .....</b>	<b>4</b>
<b>1.3 DIABETES IN SUB-SAHARAN AFRICA .....</b>	<b>6</b>
<b>1.4 RWANDA.....</b>	<b>8</b>
<b>1.4.1 Diabetes in Rwanda.....</b>	<b>9</b>
<b>1.4.2 Rwanda Diabetes Association.....</b>	<b>10</b>
<b>1.5 GAPS IN CARE.....</b>	<b>11</b>
<b>1.6 PEER SUPPORT .....</b>	<b>14</b>
<b>1.6.1 Peer Support Model.....</b>	<b>15</b>
<b>1.6.2 Peer Support in Sub-Saharan Africa.....</b>	<b>17</b>
<b>2.0 OBJECTIVES .....</b>	<b>20</b>
<b>3.0 METHODS .....</b>	<b>21</b>
<b>3.1 STUDY POPULATION .....</b>	<b>21</b>
<b>3.2 DATA ANALYSIS.....</b>	<b>21</b>
<b>4.0 RESULTS .....</b>	<b>23</b>
<b>4.1 DESCRIPTION OF RDA REGISTRY .....</b>	<b>23</b>
<b>4.2 STAKEHOLDER INTERVIEWS .....</b>	<b>25</b>
<b>4.3 CURRENT PEER SUPPORT IN RWANDA .....</b>	<b>29</b>
<b>4.4 PROPOSAL.....</b>	<b>30</b>

4.4.1	Data Collection.....	37
4.4.2	Outcome Measures .....	39
5.0	DISCUSSION .....	43
5.1	IDENTIFIED FACILITATORS .....	43
5.2	POTENTIAL BARRIERS/LIMITATIONS .....	44
6.0	CONCLUSION.....	47
	BIBLIOGRAPHY .....	48

## LIST OF TABLES

Table 1. Non-resident and Resident Provinces with Kigali Resident Districts .....	23
Table 2. Demographic Data for the 2018 LFAC Registry from last visit (2016 -2017), by Sex..	25
Table 3. Peer Leader Training Sessions.....	33



## LIST OF FIGURES

Figure 1. Flowchart RDA/LFAC Registry Eligibility, as of February 2018 .....	24
--	----

## PREFACE

The experience of learning about type 1 diabetes and meeting the wonderful people in Rwanda has been life changing. Thank you to my advisors, friends, and family who made this possible.

To my committee members, Dr. Costacou and Dr. Documet, I am so thankful for your guidance and support throughout this process. The words of encouragement and understanding that you both provided were exactly what I needed to continue moving forward. Thank you to my friends who shared in this educational endeavor and could celebrate the many parts of this journey. To my family, thank you for being my home and for being so supportive of my many adventures that I always felt brave enough to take the leap.

In Rwanda and Tanzania, I met so many amazing and inspiring individuals who worked hard towards improving the health of the people in their country. Thank you for sharing your time and knowledge with me – Etienne, Vedaste, Crispin, Alivela, Chantal, Solange, Dorothy, George, and the many others who I encountered during my trip. To Laurien, my guide and support system while in Rwanda, I am grateful for our continued friendship and shared vision.

To my academic advisor, Dr. Glynn – from the first day I arrived at Pitt to now, you have helped me navigate this new direction in my life. Thank you for always having an open door, for checking in, and for always reminding me of my potential.

And to my research advisor, Dr. Orchard, your support, guidance, and wisdom have meant the world to me. I learned so much from our conversations, not only about public health and epidemiology, but about the meaningful contributions we can have in our work. Your advice goes beyond this essay, our time in Rwanda, and this MPH program, but will stay with me throughout my life.

## 1.0 INTRODUCTION

Increasing research efforts to understand the impact of non-communicable diseases in low- and middle- income countries (LMICs) have indicated that diabetes is an area of growing concern. Diabetes mellitus is a non-communicable disease that occurs when the body cannot produce enough (Type 2) or any (Type 1) insulin to regulate the amount of glucose in the blood. Insulin production to regulate glucose is essential for preventing life threatening diabetes-related complications such as neuropathy, nephropathy, eye diseases, and accelerated cardiovascular disease. Optimal diabetes management is difficult to achieve even in high-income countries where resources are generally more available. The management of care proves even more difficult in LMICs countries where patients and their carers face barriers to a greater degree such as insufficient clinical resources and limited access to professionals extensively trained in diabetes. LMICs also face macro level challenges in achieving optimal diabetes management due to food insecurity, and a present double burden of disease where countries are affected simultaneously by both infectious and chronic diseases. These barriers to diabetes management lead to even higher mortality rates in LMICs and greater rates of diabetes complications. In addition, there is little recognition of the psychosocial factors related to diabetes care that consequently leads to little information on methods for targeting these areas to improve diabetes management.

## 1.1 DIABETES EPIDEMIOLOGY

Among adults (ages 20 – 79), it is estimated that 8.8% (425 million) have some form of diabetes, from which 79% live in LMICs. There are two main types of diabetes mellitus: Type 2 Diabetes (T2D) and Type 1 Diabetes (T1D). T2D in a person initially starts with insulin resistance, which is then followed by a progressive reduction in beta-cell insulin secretion. With the T2D diagnosis, it is still possible to delay or even prevent disease progression by implementing lifestyle changes and/or following a medication regimen. T2D is the most common type of diabetes, accounting for 90% of diabetes cases, and generally affects older adults but has recently started appearing among children and adolescents as well (*The IDF Diabetes Atlas*, 2017).

Type 1 Diabetes is characterized by autoimmune beta-cell destruction which leads to the complete inability of the body to produce insulin (American Diabetes Association, 2019). For T1D, much information of the underlying disease mechanism is still unknown although there is a strong indication of a genetic component to the disease which predisposes to the autoimmune process perhaps triggered by environmental factors (You & Henneberg, 2016). While T1D affects 5-10% of all individuals with diabetes, there is no prevention or cure available. Children and adolescents are a major fraction of the type 1 burden. The IDF (2017) estimates that there are 1,106,200 children and adolescents (ages 0 – 20) who have T1D in the world.

In addition to the two main types of diabetes, there is also gestational diabetes which occurs when there is insulin resistance due to the hormones produced by the placenta (*The IDF Diabetes Atlas*, 2017). Gestational diabetes is typically identified during the second or third trimester when there is no clear indication of diabetes prior to pregnancy and it lasts only for the duration of the pregnancy. Gestational diabetes can cause pregnancy complications due to high blood pressure and larger baby sizes for gestational age (*The IDF Diabetes Atlas*, 2017). In their report, the IDF

(2017) estimated that gestational diabetes occurred in 16.2% of live births during 2017, with 88% of cases occurring in LMICs. Women with gestational diabetes can treat this condition with a healthy diet, light exercise, and blood glucose monitoring. These methods for treating gestational diabetes are less available in LMICs and LMICs generally lack an availability of appropriate maternal care, which could account for the higher proportion of cases in these areas. Having a diagnosis of gestational diabetes can lead to the mother developing Type 2 diabetes later in life and the child born to a mother with gestational diabetes has a greater risk of developing Type 2 diabetes during their lifetime (*The IDF Diabetes Atlas, 2017*).

Additional diabetes related diagnoses are prediabetes, which includes impaired glucose tolerance (IGT) and impaired fasting glucose (IFG), and genetically based/secondary cases of diabetes. IGT is when the glucose level (following a glucose challenge) is above the normal range but does not meet the diagnostic criteria for Type 2 diabetes. Similarly, IFG is diagnosed when the fasting glucose is elevated but not meeting the diabetic level. Genetically caused and secondary cases of diabetes are infrequent but include: monogenic diabetes syndromes, diseases of the exocrine pancreas, and drug- or chemical-induced diabetes (American Diabetes Association, 2019).

Given that Type 2 is more prevalent across the world, there is an abundance of research into prevention measures and diabetes management programs for these patients. Research into these areas for Type 1 diabetes is often neglected even though the incidence of T1D is estimated to have an annual increase of 3% (*The IDF Diabetes Atlas, 2017*). This is deeply concerning since people living with Type 1 diabetes, while dependent on insulin therapy, can live a healthy life through maintaining proper diabetes care. For this reason, this paper focuses on the management of Type 1 diabetes and proposes a method for improving access to social and clinical care.

## 1.2 TYPE 1 DIABETES MANAGEMENT

As public health awareness continues to grow around non-communicable diseases in LMICs, a substantial need for greater support in managing care is becoming apparent. The American Diabetes Association (ADA) annually updates their Standards of Medical Care in Diabetes to reflect current evidence-based recommendations for practicing physicians in treating diabetes. There are also multiple international organizations, such as the World Health Organization (WHO), the International Diabetes Federation (IDF), and the International Society for Pediatric and Adolescent Diabetes (ISPAD), that report standards for diabetes care targeted towards a broader healthcare professional audience in the global context.

The standard of care for T1D management includes insulin treatment, blood glucose monitoring, nutritional management, physical activity, and psychosocial support (Chamberlain et al., 2017; G. Ogle, Middlehurst, Silink, & Hanas, 2017). For insulin treatment, there are three traditional forms of insulin: short acting (regular) lasts 5 – 8 hours, intermediate acting (neutral protamine Hagedorn or NPH) lasts 12 – 24 hours, and pre-mixed (regular and NPH). Analogue insulins, which are rapid and long acting, are another type of insulin available in some countries, however, they are substantially more expensive. There are also different insulin regimens people with T1D can follow. The basal bolus regimen more closely mimics the body's natural physiology (American Diabetes Association, 2019; G. Ogle et al., 2017). The guideline for the basal bolus regimen suggests patients take multiple injections of regular insulin (70% of daily amount divided between 3 – 4 injections) before meals and one long acting insulin injection in the evening (G. Ogle et al., 2017). Because these are smaller increments of insulin, the basal bolus regimen provides more flexibility in accommodating for meal size and food contents. Due to the high cost of analogue insulins, in resource limited settings there is still a need for the commonly used

combination insulin regimen: twice daily combinations of regular and NPH insulin. This regimen is instead of the basal bolus regimen. A major problem with the combination insulin regimen is that the insulin dose for the next 12 hours is set. One has to eat and exercise exactly as anticipated or else risk poor control and/or the extremely concerning issue of hypoglycemia if the carbohydrate intake is less, or exercise greater, than anticipated. In an economically challenged society with major food insecurity, this is a major barrier.

Another component of T1D management is blood glucose monitoring, measuring the amount of glucose in the blood by applying a drop of blood to a disposable test strip which is inputted into a blood glucose monitoring device. If test strips are widely available, then ideally blood glucose levels (BGL) should be checked prior to every meal and before bedtime. However, if test strips are limited, then testing BGL a couple times per week at different times of day is still helpful in monitoring. Glycated hemoglobin (HbA1c) measures the average BGL over the past 2 – 3 months by testing for the amount of glucose attached to hemoglobin which is turned over every three months. Blood glucose monitoring is important for identifying the ideal individualized medication regimen appropriate for one's lifestyle. This component of diabetes management, however, is dependent on availability of medical materials and access to specialized medical equipment.

Additionally, nutrition plays a large part in diabetes management. Carbohydrates need to be closely monitored to ensure the amount of insulin matches the amount of 'carbs' to be ingested. Physical activity is supported and encouraged although BGL should be tested before and after exercising, and the amount of food and times of consumption should be adjusted depending on the intensity level of the exercise. In addition to the lifestyle aspects of diabetes management, there are also recommendations for diabetes education and psychological care (G. Ogle et al., 2017).

Diabetes education should start immediately at the time of diagnosis and should include practical knowledge, dispelling of myths, and promotion of self-management. To ensure accessibility for multiple ways of learning and literacy, visuals such as diagrams, drawings, acts, videos, guidebooks, etc. should be used to communicate the material (G. Ogle et al., 2017). Appropriate nutrition can be difficult to maintain and receiving a sufficient amount of diabetes education at initial diagnosis can be difficult to achieve. Sometimes, the education received at initial diagnosis or soon after does not include resources for addressing the psychological effects a T1D diagnosis can have on a child.

### **1.3 DIABETES IN SUB-SAHARAN AFRICA**

In sub-Saharan Africa, an estimated 15.9 million adults (18 – 99 years of age) have some form of diabetes mellitus including IGT, for a prevalence of 3.1% (*The IDF Diabetes Atlas, AFRICA Highlights*, 2017). This region also has the highest proportion of undiagnosed diabetes; the International Diabetes Federation (2017) reports that in sub-Saharan Africa 69.2% of people with diabetes do not know they have this disease. Of further concern are estimates that this region will have the largest predicted increase (156%) in diabetes between 2017, where there were 16 million people with diabetes, and 2045, predicted to be 41 million people with diabetes (*The IDF Diabetes Atlas, AFRICA Highlights*, 2017). These figures suggest that there is a large need in sub-Saharan Africa for improved understanding of diabetes epidemiology and feasible means for patients to access culturally appropriate diabetes care. There continue, however, to be challenges in accomplishing this level of understanding, including gaps in care, as discussed in section 1.5, as well as limitations in reliable data and country-specific information.



The significant increase in the risk and prevalence of diabetes throughout LMICs is a result of rapid demographic, sociocultural, and economic transitions (Atun et al., 2017; Boutayeb, 2006). As populations grow, the age distributions are changing, with increases in lifespan and decreases in fertility rates. In addition, sociocultural aspects of many countries are being influenced in diet and lifestyle by westernized practices. The changes in health across the globe are especially evident when examining the leading causes of death. Previously, in sub-Saharan Africa the leading causes of death were infectious diseases such as HIV/AIDS, lower respiratory infections, malaria, and vaccine-preventable diseases (Atun et al., 2017). Non-communicable diseases such as cardiovascular disease, cancer, and diabetes were associated with countries that had longer lifespans and higher economies (Boutayeb, 2006). However, due to improved hygiene and sanitation practices eliminating many vectors of infectious disease, today every country is seeing an increase in non-communicable disease associated morbidity and mortality.

Lack of reliable data makes it difficult to know the extent to which countries in this region are affected by diabetes. The IDF (2017) has identified sub-Saharan Africa as the region with the highest proportion of deaths due to diabetes among people under age 60, at 3 out of 4 (73%) deaths. However, this estimation is based on only a handful of reliable reports (*The IDF Diabetes Atlas, AFRICA Highlights*, 2017). Data for this region has been described as insufficient in quality of conduct, analysis, and reporting (Rehfuss et al., 2016). For mortality rates, many deaths go unreported or there are inadequate records on cause of death (Atun et al., 2017). In addition, when conducting and recording consistent testing results, such as HbA1c, staff run into problems with lack of equipment or inconsistent methodology of recording the data (Rehfuss et al., 2016). On similar lines, the lack of resources also affects proper diagnoses, which leads to underestimating the true incidence and prevalence of diabetes in a country. However, as Rehfuss et al. (2016)

suggested as a needed shift, there is now a transition occurring among local policy makers from receiving external assistance towards evaluating national or local solutions. Many local governments in sub-Saharan Africa are exchanging insights through summits and conferences and are creating strategic plans that specifically address non-communicable diseases at their respective national level. Better monitoring, evaluation, and data collection of diabetes associated mortality and morbidity is needed in LMICs but this begins by identifying and addressing the gaps in care at the local level.

#### 1.4 RWANDA

Rwanda is a land-locked country bordered by the Democratic Republic of the Congo (DRC), Burundi, Tanzania, and Uganda. As of 2015, the population of Rwanda had reached 11.3 million, a 2.1% increase from the 2012 Population and Housing Census (Rwanda, 2018). The rate of population increase is expected to fall as the fertility rate decreased between 2005 (6.1) and 2014 (4.2). Population breakdown by district has the capital city, Kigali, at 11%. Following Kigali, the provinces and their proportion of the population are East (25.6%), South (24%), West (23.3%), and North (16.4%). In Rwanda, it is estimated that 85% live in rural areas (*Republic of Rwanda Non-communicable Diseases Policy*, 2015). The age distribution of Rwanda is quite striking, 54% are under the age of 19 and only 3% are 65 years and older (Rwanda, 2018). One contributor to this age distribution was the genocide that occurred in Rwanda in 1994 where it is estimated 1 million people were killed (Binagwaho et al., 2014).

Government initiatives by the Rwanda Ministry of Health (MOH), through its Rwanda Biomedical Center (RBC), include adopting a universal healthcare system, *Mutuelles de Sante*,

and the decentralization of non-communicable disease care from the district hospitals to the health centers. Implemented in 2004, Mutuelles de Sante has evolved into a three tier payment system and, along with grants received from The Global Fund, the government is able to cover the premiums and co-payments of many of the poorest patients (Binagwaho et al., 2014). In addition, the MOH aims to increase access to chronic disease care by having more trained staff at the local level. Creating Non-communicable Disease (NCD) Clinics at the health centers was undertaken because evidence demonstrated the rapid increase of chronic disease among Rwandan citizens. During 2013, these diseases accounted for 51.9% of all district hospital outpatient consultations (*Republic of Rwanda Non-communicable Diseases Policy*, 2015). As of 2015, there were 41 district hospitals and 400 health centers located throughout the country (S. L. Marshall et al., 2015). Country officials and the Rwanda Biomedical Center confirmed the integration of these new NCD clinics at all government run health centers throughout the country by June 2018 (Afadhali, 2017).

#### **1.4.1 Diabetes in Rwanda**

Compared to the other countries in the sub-Saharan Africa region, Rwanda is estimated to have a higher proportion of undiagnosed cases of diabetes, at 76.3%, when compared to the regional proportion (69.2%) (*The IDF Diabetes Atlas, 8th Edition, Rwanda*, 2017). To calculate this estimate for Rwanda, the IDF (2017) applied a value from the generalized linear random effects model based on IDF regions and the income level of the country to estimate the rates of undiagnosed diabetes. The reasons for this higher proportion in Rwanda could be due to a rapidly rising population, changing economy, proportion of the population in rural areas, possible lack of access to formal medical care, and slow advancement in diagnostic measures. Estimates from data collected from August 2011 to July 2012 indicate that the prevalence of Type 1 diabetes in Rwanda

is 16.4 per 100,000 among those less than 26 years of age (S. L. Marshall et al., 2015). In this same study, the incidence of T1D remained consistent from 2007 – 2011 at 2.7 per 100,000 for those less than 26 years old (S. L. Marshall et al., 2015). In addition, perceptions about T2D assessed by questionnaire in Rwamagana, a district of Rwanda in the East province, indicated that diabetes understanding and perceived susceptibility of having diabetes were low among residents (Mukeshimana & Nkosi, 2014). Mukeshimana and Nkosi (2014) further observed that out of the 331 respondents, only 25.6% believed that western medicine would cure diabetes and 18.3% stated they would consult traditional healers for diabetes treatment. While this study is not generalizable to the nation, similar perceptions have been observed in Kigali and other regions of Rwanda.

#### **1.4.2 Rwanda Diabetes Association**

The Rwanda Diabetes Association (RDA) is a non-governmental organization that was founded by Francois Gishoma in 1997 to address the rising impact of diabetes among Rwandan youth (“Our Story – Rwanda Diabetes Association,” 2019). The RDA primarily provides care, including insulin and blood glucose testing supplies donated by Life for A Child (LFAC)<sup>1</sup> and Insulin for Life. More recently, the RDA has expanded to provide diabetes camps for youth during the summer, specialized trainings for healthcare providers and educators, and patient educational sessions on diabetes management.

---

<sup>1</sup> The LFAC program helps 18,000 youth living with type 1 diabetes in 42 countries. LFAC partners with in-country diabetes centers and their staff to provide materials, trainings, and education for youth on diabetes management. These provisions have included insulin and syringes, blood glucose monitoring equipment and test strips, HbA1c testing, and additional means for clinical care. LFAC began its partnership in Rwanda in 2009 with the RDA.

While the organization was originally based in Kigali, the capital city, over time the RDA has expanded to conduct clinic visits throughout every province of Rwanda to ensure youth have better access to diabetes care. These quarterly visits were led by local RDA staff nurses at district hospitals or clinics. During these clinic visits, the nursing staff led on-site diabetes education sessions, conducted diabetes testing and collected basic health measures, spoke one-on-one with patients about successes and areas for improvement, and provided diabetes materials and medication. However, these quarterly clinic visits to district hospitals were largely funded by a research grant from National Institute of Diabetes and Digestive and Kidney Disease (NIDDKD) to the University of Pittsburgh. Since this grant finished, resources have become very limited. The limitations continue due to LFAC, the main supplier of insulin and blood testing supplies, also having to cut-back on its frequency and quantity of disbursements. For this reason, the RDA is undergoing a transition in which LFAC will continue to support those patients seen at the RDA in Kigali, while the care for the rest of the country will be provided by the Ministry of Health (MOH) through the RBC and the new NCD clinics.

## **1.5 GAPS IN CARE**

In reality, trying to meet the standards of care, described in section 1.2 above, proves difficult even in resource rich settings and high-income countries. The lack of available care is amplified in LMICs where there are often inadequate resources to meet a sustainable level of basic diabetes care. These gaps in care are especially evident in the low number of professionals adequately trained in diabetes, insufficient diabetes education, food insecurity, and little acknowledgement of psychosocial factors related to diabetes.

The present double burden of disease in many LMICs has led to strained resources across health care systems. For some, non-communicable diseases are not viewed as a large enough issue to permit the distribution of copious amounts of resources and funding. This is due to the dual problem countries face when simultaneously combating diseases such as malaria, tuberculosis, and HIV/AIDS with cancer, diabetes, and chronic respiratory diseases. Non-communicable diseases can easily be overlooked until their complications become severe enough to rouse attention. However, given the projections for sub-Saharan Africa and LMICs overall, if effective measures are not taken now then the negative outcomes associated with these non-communicable diseases will rapidly get worse (Atun & Gale, 2015). Health systems in LMICs also need to assess their ability to care for people undergoing infectious and noninfectious comorbidities. This interaction is putting a lot of stress on staff and many healthcare professionals are not trained well enough to respond to the problem as quickly as needed.

Ample professional training leads to closing gaps in care by reducing the misdiagnosis of diabetes. Recent studies have shown that for a sick child, diabetes could be mistaken for cerebral malaria or dysentery (Makani et al., 2003; G. Ogle et al., 2017; Rowlands et al., 2018). In a survey conducted by LFAC, deaths from misdiagnosis of diabetic ketoacidosis (DKA) were considered likely to very likely among youth with T1D. These youth then faced the possibility of dying before even being able to receive any kind of diabetes treatment (G. D. Ogle, Middlehurst, & Silink, 2016). More training is needed at the professional level for recognizing symptoms of diabetes, distinguishing these symptoms from other diseases, and confirming diagnosis through clinical measures. In addition, increasing the quality and amount of training for healthcare professionals on non-communicable diseases, especially T1D, would also improve the level of care people receive when they are first diagnosed. At the initial diagnosis, healthcare professionals often are

only able to communicate a short amount of information given the amount of time they have per patient. This conversation with the provider could be heavy with medical language and may not include ways to cope with psychological or social issues. Widening the scope of clinical and professional trainings to include more topics and types of personnel would improve the value of information received at initial diagnosis.

Food insecurity (FI) greatly affects successful diabetes management and is especially relevant for maintaining a continuous insulin regimen. A household is food insecure when there is insufficient means of obtaining consistent, adequate, and nutritional food while also possibly having to rely on emergency supplies or scavenging (Cheng et al., 2013). Studies have found that there is an association between FI and poorly controlled diabetes such as lower usage of insulin, higher HbA1c measures, and lower nutrition (Cheng et al., 2013; Mendoza et al., 2018). Alleviating FI for those living with diabetes could relieve many of the other factors possibly linked to the burden of diabetes care. Hospital costs for diabetes-related complications lead to many further issues for a patient and can lead to additional psychosocial factors affecting health (Marjerrison, Cummings, Glanville, Kirk, & Ledwell, 2011; Mendoza et al., 2018). Mendoza et al. (2018) specifically looked at food insecurity among youth and young adults (YYAs) with T1D and found that it was associated with high risk glycemic control. YYAs from FI households had 2.37 (95% CI: 1.10, 5.09) higher odds of high-risk glycemic control compared to YYA in non-FI households (Mendoza et al., 2018). They also found though that the highest levels of FI were associated with lower HbA1c, which Mendoza et al. (2018) related to previous findings where the body at that level of FI goes into a fasting state. While only one of these studies was conducted in Africa, Cheng et al. (2013) in Kenya, many of the findings align with food insecurity issues in Rwanda. Youth at the RDA do experience FI and sometimes do not know when nor what their

next meal will be. Foods that are most likely affordable for youth are the least nutritious, unplanned, and are calorie/carbohydrate dense. Without consistent knowledge of one's next meal, it is hard to plan any kind of diabetes management. Due to FI, youth with T1D in Rwanda often have to face the risk of hypoglycemia, due to taking medicine but then not having food, or hyperglycemia, eating but not having access to medicine.

Even if healthcare professionals underwent increased training in diabetes and food was more secure, there are still persistent logistical issues in LMICs with receiving and distributing medicine and medical supplies. LMICs face issues with cost of medication, health system level and individual level affordability, and consistent availability. Issues with cost stem from the monopolized quality of the global insulin market, lack of variability of drug type on the market, and high taxation (Beran, Ewen, & Laing, 2016). Rwanda faces these same issues in trying to obtain diabetes medication and clinical tools from external sources. There are additional problems reported on distributing medications to rural areas and having sufficient storage with adequate refrigeration. Overall, the path from manufacturer to patient faces many challenges that require an innovative comprehensive solution.

## **1.6 PEER SUPPORT**

At its foundation, the concept 'peer support' is the "giving of assistance and encouragement by an individual considered equal" (Dennis, 2003). Over the last few decades, peer support has been applied in various ways within a number of disciplines. The adoption of peer support in the health sector connects to the shift from focusing on purely clinical treatment of a disease to, instead, advancing disease prevention methods and health promotion. There has been significant evidence



that establishing and/or improving social relationships has a positive effect on an individual's health and well-being. For these reasons, this paper proposes implementing a peer support network (PSN) for youth with T1D in Kigali, Rwanda to improve diabetes management by addressing the gaps in care previously described.

### **1.6.1 Peer Support Model**

There have been a few models developed for implementing peer support programs in health focused areas. The model chosen for this project was designed by Edwin Fisher, PhD, who founded Peers for Progress. Dr. Fisher has developed a framework that outlines the participants for peer support and four key functions peer support programs should practice that target social support within a culturally relevant structure. The four functions include: (1) assistance in applying disease management or prevention plans in daily life (2) emotional and social support; (3) linkage to clinical care; and (4) maintaining ongoing support (Boothroyd & Fisher, 2010; Fisher et al., 2014; Fisher, Earp, Maman, & Zolotor, 2010). These areas closely align with the identified needs for youth with T1D in Rwanda.

Dr. Fisher and Peers for Progress further suggest including evaluation methods, inter-program communication, and peer support advocacy when planning and implementing peer support programs. These additional areas assist in enabling a peer support program to be effective and sustainable (Zhong, Wang, Fisher, & Tanasugarn, 2015). Another important component that Dr. Fisher emphasizes is the cultural adaptability of any peer support program. To maintain cultural relevance, peer support program participants are those that reflect the culture of the target population. Peer leaders for these programs are individuals that share culture, race/ethnicity, or a common disease with the peers they are leading. Through Peers for Progress, this peer support

framework has been implemented in Uganda, China, Cameroon, and many other locations. In each case the program demonstrated its flexibility and cultural adaptability.

When discussing implementation measures for “good” peer support, Dr. Fisher et al. (2014) includes considerations for selecting peers, organizational structure, and reaching marginalized populations. One aspect of peer support Dr. Fisher elaborates on is the commonality of disease among peers, “people like me” and multimorbidity (Fisher et al., 2014). Populations of focus for peer support members and peer leadership can be defined by one disease only, multiple diseases, or focus on a different area of health such as disease severity. For Rwanda, often there are multiple underlying health concerns for a person with T1D: never strictly just one disease. While this project does focus on T1D, understanding the holistic health needs of people in this population is important. The peer support program for Kigali will not exclude individuals due to the occurrence of comorbidities, however the primary focus will be on promoting T1D management. Managing diabetes care alongside comorbidities may be addressed through educational modules in this program, but direct care for additional ailments should be sought from other resources.

Furthermore, Dr. Fisher promotes integrating mental health and psychosocial health needs into peer support models. Understanding these measures throughout project implementation, execution, and evaluation will help sustainability efforts for the peer support program. To have inter-group support, this proposal includes expanding peer support groups into a peer support network (PSN) where programs in different areas of Kigali and Rwanda can communicate successes and challenges. The interconnected nature of the PSN assists in addressing areas of mental and psychosocial health. There is greater awareness within the peer support groups of emotional needs of the youth, which helps in immediately addressing these needs, and there is known social connectedness throughout the county. In addition, the PSN is a means for achieving

sustainability of the peer support program by providing constant feedback on program progress, internal and local resources for peer and leader support, and maintenance of a broader social network for the youth.

### **1.6.2 Peer Support in Sub-Saharan Africa**

Peer support has been utilized in a number of countries in Africa to address challenges with maternal health and with infectious diseases, especially HIV prevention through anti-retroviral treatment management. It is only recently that some countries in this region have reported the use of peer support for disease prevention and management of chronic diseases. Within this scope of non-communicable disease, only a few countries have specifically applied peer support programs to target the unique needs of their citizens living with diabetes.

Examining recent peer support programs for diabetes in three sub-Saharan Africa countries -- Cameroon, Mali, and Uganda -- provides insights into the current methodology and outcomes of this practice. All three of these programs only included adults (age > 18 years) in their respective studies – mean age 57.15 (Cameroon), median age 53 (Uganda), and mean age 52.5 (Mali) (Assah, Atanga, Enoru, Sobngwi, & Mbanya, 2015; Baumann, Josphine, Agatha, Frederick, & Betty, 2014; Debussche et al., 2018). The participants had all been diagnosed with Type 2 diabetes and the average duration of disease varied between Uganda (5 years) and Cameroon (10 years), while this measure was unreported in the Mali study. The aims for each study were to improve diabetes self-care behaviors, glycemic control, social support and emotional well-being, linkages to health care providers, and assess sustainability.

The application of peer support did vary between these three groups. Assah et al. (2015) compared a peer support intervention and usual clinical care through a non-randomized controlled

trial over a 6-month period in Cameroon. In this study, subjects in the control arm were matched to the 96 subjects in the intervention on sex and age. Assah et al. (2015) used a culturally adapted structured community based multi-level peer support intervention which included group meetings, personal encounters, and telephone calls. In the Structured Type 2 Diabetes Self-Management Education by Peers (ST2EP) program, Debussche et al. (2018) conducted an open-label randomized control trial over 1-year of peer-led diabetes education ('Learning Nests') in the community (n=76) compared to conventional care alone (n=75) based out of Bamako, Mali. Specifically, the intervention led by peer-educators included three courses which then each had four thematic sessions addressing key components of diabetes management. These sessions included culturally adapted booklets tailored to different literacy levels for the peers and instructional booklets for the peer educators. While these previous two studies both took place in the capital cities of their respective countries, Baumann et al. (2014) applied a peer support intervention in a rural community of Uganda, Mityana, to measure the feasibility and effectiveness of peer support in this setting. Their aim in the pre-post quasi-experimental study was to train an equal number of "champions", who have a more leadership role, and "partners", who have a peer role. Champions and partners both received the same training in diabetes management and the Champions received an additional hour long training on supportive communication skills (Baumann et al., 2014). After training, recruited champions (n= 19) and partners (n=27) were paired for the duration of the study, 4 months, and directed to make weekly contact either through phone calls (phones provided by the study) or in-person.

The results of these studies indicate that peer support can help improve diabetes control. The primary outcome examined in each study was a difference in HbA1c levels. Each study reported a significant difference in HbA1c levels: in Cameroon, there was a -3.0% reduction in the

intervention group and a -1.3% reduction in the control group and this was a significant difference between groups ( $p < 0.001$ ); in Uganda, HbA1c decreased from 11.01% to 8.31% ( $p < 0.005$ ); and Mali's intervention arm had a greater reduction in HbA1c levels compared to the control group [-1.05 (sd=2) vs -0.15 (sd = 1.7)] (Assah et al., 2015; Baumann et al., 2014; Debussche et al., 2018). Mali also reported significant changes in self-care behavior ( $p < 0.001$ ) as measured through the Survey of Diabetes Self-Care Activities (SDSCA). Baumann et al. (2014) presented meaningful qualitative data through the logs and journals kept by the champions and partners where they recorded statements of meaning and improvements in diabetes management. Included in this narrative, participants reported recognizing the isolation they felt with diabetes before peer support. The statement "You are not alone with diabetes" included in the booklets prompted this sense of awareness.

While these studies do provide insights into peer support application towards diabetes control, they do not delve into the specific qualities of T1D. In addition, Baumann in Uganda did not find any statistically significant outcomes in emotional support; however, this could have been due to limitations of study design with the sample size being smaller than required for accurate analysis. For the same study though, youth in Uganda did continue the relationship with their peer partner beyond the life of the study, although at a lower frequency. Providing a social environment did engage youth in cultivating relationships among those with shared experiences who could provide emotional support. Strengths of these designs are the culturally adapted implementation for each country, the flexibility of peer support, and the significant effect peer support can have on clinical measures of diabetes.

## **2.0 OBJECTIVES**

The objective of this research is 1) to describe the current need for a peer support network to improve diabetes management among youth in Rwanda based on recent reports of clinical status and 2) to propose an outline for implementing a peer support program through the Rwanda Diabetes Association centrally located in Kigali, Rwanda. Based on key findings in the literature and demonstrated clinical needs, this proposal provides an overview of how peer support programs, designed specifically for type 1 diabetes education and management, are particularly suited for reducing youth being lost to follow-up and improving their health outcomes.

## **3.0 METHODS**

### **3.1 STUDY POPULATION**

The targeted population included in this study are patients of the Rwanda Diabetes Association through the Life For A Child (LFAC) program. Participants of LFAC must be less than 26 years of age and demonstrate a need for assistance in diabetes care. In Rwanda, participants are typically diagnosed at a local clinic in their area of residence and then they are referred to the RDA by a healthcare provider. While the RDA is located in the capital, Kigali, participants reside across the country from every province (North, South, East, West, and Kigali).

### **3.2 DATA ANALYSIS**

In an effort to improve follow-up rate, the RDA is restructuring its methods for monitoring and evaluating the health of youth diagnosed with Type 1 diabetes. This restructuring has included developing an updated registry that will be implemented as a master list for continued follow-up. Patient data were reviewed to identify those meeting the following eligibility criteria: age less than 26 years and having been seen at the RDA clinic in Kigali at some point in time since 2016. In addition, the updated registry permits the inclusion of those living outside Kigali province but have the RDA listed as their primary clinic. For this reason, there was an additional binary variable created, “non-resident.” If a patient met the inclusion criteria and lived outside Kigali but the RDA was their primary clinic, then this individual was assigned ‘1’ for the “non-resident” variable,

otherwise they were assigned '0.' After determining this registry, descriptive statistics, loss to follow-up, and mortality were assessed. Variables were checked for normality. In cases of variables not being normal, a non-parametric test was used for evaluating differences between gender. For categorical variables, chi-squared tests were conducted. Data were processed and analyzed using Microsoft Excel and SAS 9.4 (SAS Institute, Cary NC). Additional data were collected through informal interviews with stakeholders at the RDA and the Tanzania Diabetes Youth Association (TDYA). With the TDYA, we conducted an on-site informal focus group with peer leaders and peer group members.



## 4.0 RESULTS

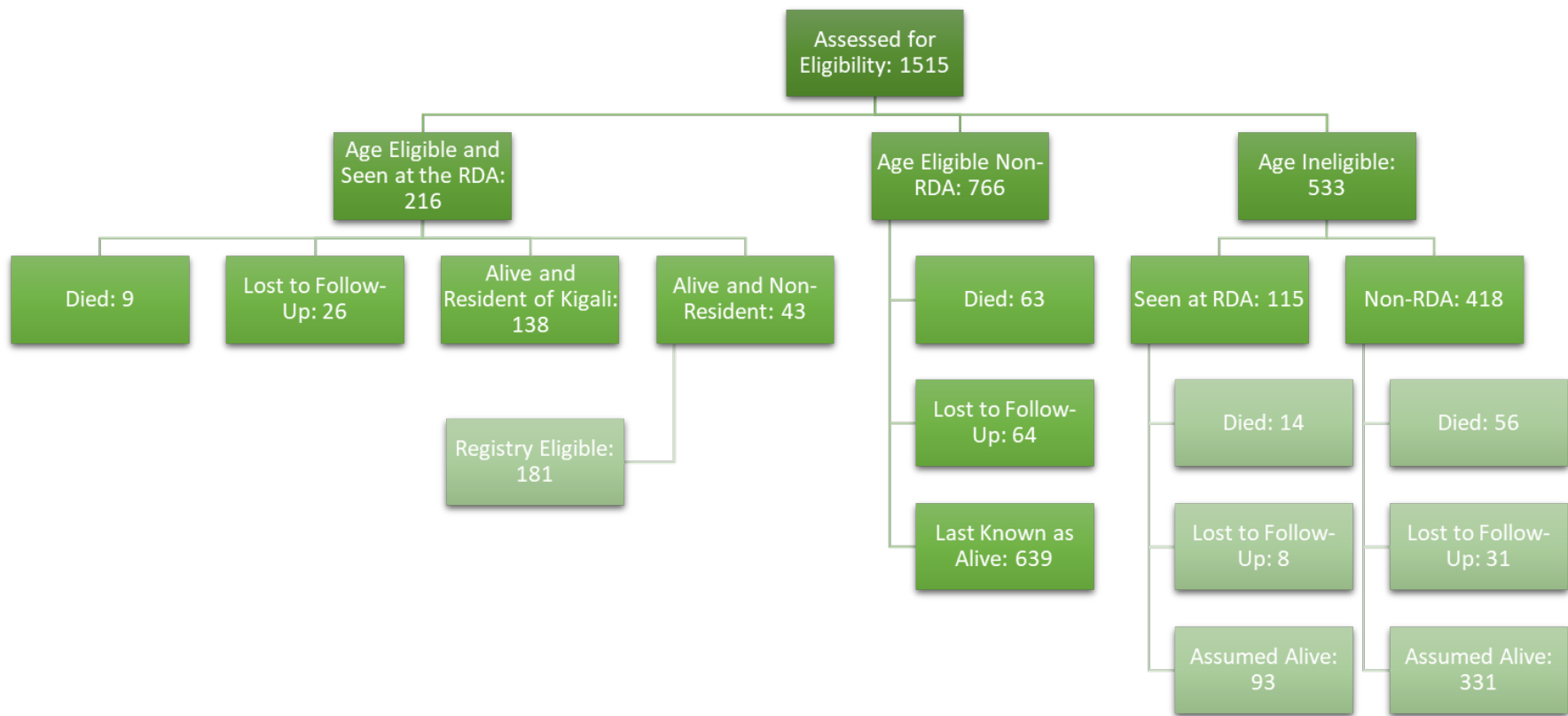
### 4.1 DESCRIPTION OF RDA REGISTRY

This project evaluated 1,515 youths for eligibility into the updated LFAC/RDA registry (See Figure 1). From these 1,515 youths, 533 (35.2%) were found to be age ineligible, 766 (50.1%) were age eligible but did not have the RDA as their primary clinic, and 216 (14.3%) were eligible for further evaluation. Of the 216 found age eligible (<26 years old) and attended the RDA clinic since 2016, 9 (4.2%) had died and 26 (12%) were lost to follow up. In total, 181 were found to meet the criteria for being included in the LFAC/RDA registry.

Of the 181 youth found to be eligible, 43 were non-residents of Kigali listing one of the other four provinces as their primary residence. There are 138 youths that live in Kigali and the breakdown of the number of youths per province and Kigali district is shown in Table 1.

**Table 1. Non-resident and Resident Provinces with Kigali Resident Districts**

Provinces (Districts)	N =181
	% (N)
Kigali	76.2 (138)
(Gasabo)	38.4 (53)
(Kicukiro)	26.8 (37)
(Nyarugenge)	31.9 (44)
*Missing	2.9 (4)
North	3.9 (7)
South	10.5 (19)
East	2.8 (5)
West	6.6 (12)



**Figure 1. Flowchart RDA/LFAC Registry Eligibility, as of February 2018**

Presented in table 2, additional descriptive information on the RDA youth including median (inter-quartile rang) of current age, age of onset, duration of disease and follow-up year. Also, the proportion of youth HbA1c measures from the most recent clinic visit are reported by group. Below 7.5% is the clinical recommendation for youth with T1D, however, among reported youth HbA1c measures more than 50% are at a greater than 9% HbA1c level. This indicates that the youth have experienced poor glycemic control over the previous 2 – 3 months.

**Table 2. Demographic Data for the 2018 LFAC Registry from last visit (2016 -2017), by Sex**

	<b>Overall</b>	<b>Male</b>	<b>Female</b>	<b>p-value</b>
	N= 180	N = 86	N = 94	
Age, yrs <sup>c</sup>	20 (16.5, 23.5)	20 (16, 23)	21 (17, 24)	0.218
Age at Onset, yrs <sup>ac</sup>	14 (11, 18)	14 (10, 18)	14 (11, 18)	0.728
Duration of Diabetes, yrs <sup>c</sup>	5 (3, 8)	5 (4, 7)	5 (3, 8)	0.764
Follow-Up, yrs <sup>c</sup>	4 (2,6)	5 (2, 5)	4 (2, 7)	0.646
HbA1c (% , N) <sup>b</sup>				0.1092
<= 7.5	22.3 (37)	23.5 (19)	21.2 (18)	
7.5 < HbA1c <=8.9	19.9 (33)	25.9 (21)	14.1 (12)	
> 9.0	57.8 (96)	50.6 (41)	64.7 (55)	

a. Missing 8 values  
b. Missing 15 values  
c. median (IQR)

## 4.2 STAKEHOLDER INTERVIEWS

For the purpose of establishing a case for, and the role of, a Peer Support Network in Rwanda, this project sought out input from stakeholders both in Rwanda and in neighboring Tanzania. These were informal interviews with clinical staff at the RDA, youth with T1D in Rwanda, and members

of the Tanzania Diabetes Youth Association (TDYA). Many of the clinical staff at the RDA have been involved with the clinic for a number of years. Staff members include providers, nurses, administration, and health educators. Youth with T1D were either current patients of the RDA, had previously attended the RDA, or were previously eligible for the LFAC support. The TDYA seeks to improve diabetes care among youth and has incorporated a couple of strategies to address the variety of psychosocial factors affecting diabetes management including a microfinance program and a youth led peer support program. Previously, the TDYA were part of the Tanzania Diabetes Association (TDA) based in Dar es Salaam, Tanzania but have recently been pursuing government recognition as a completely youth-led formal organization. Members of the TDYA peer leader board, additional peer leaders, and other associates participated in these informal, semi-structured interviews.

Due to the recent shipment of diabetes supplies from an external source, some of the first topics discussed among RDA staff were difficulties with supply and transportation. Insulin gets shipped but then can remain in customs for risky amounts of time and in improper storage conditions. Adding further complications to the shipment and receipt of medicine, there is a lack of available staff to collect and pay for the insulin and supplies even if the shipment does successfully go through customs. Collecting the medicine and supplies requires a full day of staff time, often additional costs, and a reliable large enough vehicle. Depending on traffic conditions, even once the supplies are picked-up the journey from the airport is another concern. There could be significant amounts of traffic making the duration of the trip longer than expected, and in inclement weather or extreme heat this could have added complications.

Similar concerns with supply and transportation were brought up by staff and youth in regard to the clinic visits to the other provinces. Reaching the more rural areas of Rwanda is

difficult. Staff need to make sure there has been a sufficient amount of advance notice that there is an upcoming visit. This is so youth do not miss their opportunity to being seen. Since for some youth the clinic visit is still far away, there has to be enough time to make travel arrangements. Again, these are full day events both for staff and for the youth and their carers that come to the clinic visit. This means missing school, work, or possibly both in order to attend the clinic visit. It is also difficult for staff to predict the amount of supplies they will need for the day. This sometimes leads to running out of supplies without the ability of restocking or having too many supplies that have to remain in less than ideal storage conditions for the day. For staff transportation to the clinic visits, they can only bring what can fit in their vehicle and sometimes staff encounter major traffic issues with limited ways of contacting the visit site.

During the informal interviews, members of the TDYA peer leader executive board, provided more information on the experience with the microfinance project and the larger concern around employment while living with type 1 diabetes. The microfinance program received external funding and was disbursed among select youth with T1D who demonstrated a financial need for either job training or had already established businesses that needed additional capital. While this project did increase vocational training for a few individuals, the microfinance project also had many challenges. Family members often took advantage of the funding. In one case the family bought non-approved items and kept any kind of profit from the youth who had officially received the funding. This resulted in the funds or items of equal value being recollected from the family since it was not benefitting the youth in any way. Another issue that occurred was having vocational training or returning to school, but still having problems finding employment. In both cases, lack of understanding and stigma play a larger role in the outcome. There are families that completely disregard their child if they are diagnosed with T1D or any kind of chronic disease, as

reported by the TDYA leaders and by youth in Rwanda. Families stop sending them to school or lie about their diagnosis to others. This often leads to the youth rarely receiving proper diabetes treatment. This is also evidence that youth with T1D, while possibly having a lack of social support, may also not have any kind of at-home support.

Discussed during the focus group, role models could improve the perceptions of living with T1D among youth. When discussing employment and jobs, the TDYA stated that they were usually the only person with a chronic disease at their place of employment. Given the needs required for proper diabetes management, employers would get frustrated with the breaks and glucose testing. The youth with T1D would have feelings of inadequacy reinforced through the aggravations of their employer. Experiencing this job discrimination is very detrimental on a person's mental well-being, which then negatively affects their health. Role models could provide examples of successful employment experiences, possibly discuss pointers on navigating conversations with employers, and demonstrate that people can excel while living with T1D. As life expectancy continues to increase in LMICs, connecting with those that have successfully aged while living with a chronic condition would be helpful in many areas.

Diabetes education and knowledge at initial diagnosis was also discussed by all stakeholders. Often this was rushed through at the clinic and led to more fear rather than understanding. There is no connection made for the patient to reach out to others living with the same disease. Many youth expressed feeling alone when they were diagnosed. Sometimes they would receive the diagnosis when they were by themselves because no family could come with them. Healthcare providers would deliver the diagnosis, very briefly discuss diabetes management, and then leave the youth for their next patient. As described in these informal interviews, the system of delivering a diagnosis is in need of improvement.

### 4.3 CURRENT PEER SUPPORT IN RWANDA

Targeting the psychosocial factors of health through peer support has only been implemented in Rwanda in a limited context. Previously, there have been a few organizations that have utilized a form of peer support program or community health worker (CHW) group support to access patients with HIV and infant mortality. The Kabeho Mwana project, supported by the Rwanda Ministry of Health from 2006 to 2011, developed CHW peer support groups in 6 districts throughout Rwanda (Langston et al., 2014). The Kabeho Mwana project was part of a much larger national project for improving ‘care seeking’ behavior and involved the training of over 6,000 CHWs. Care seeking behavior is when people utilize their healthcare resources for prevention and treatment. The HIV peer education program, implemented by the Rwandan Red Cross Society, was established at fifteen secondary schools within one district, Bugesera, located in the East province (Michielsen et al., 2012). The HIV peer program trained five students who then were tasked with educating their fellow students at events held at the school. The Kabeho Mwana project did see improvements in use of care, however the CHW’s, while community-based, were not necessarily direct peers and may not have the more intimate knowledge of living with a chronic condition that they could relate to their clients. The HIV peer education program expressed that youth were hesitant to discuss HIV and sex with their peers which was a large limitation to their study. In addition, their methods did not target behavior change which prompted Michielsen et al. (2012) to propose instead targeting improved decision-making skills and empowering youth in more holistic ways.

While these programs present on the application of social/peer support and how it has been implemented within Rwanda, they do not provide information on the application of peer support for chronic diseases. At this point in time, there are no established formal peer support programs

for type 1 diabetes or general diabetes mellitus in Rwanda. The development and implementation of the following peer support network proposal for youth with T1D would be the first of its kind in Rwanda.

#### **4.4 PROPOSAL**

This proposal for a peer support network in Kigali, Rwanda draws on the already established cultural, environmental, and social components present in this country. As previously discussed, Rwanda faces many challenges in access to optimal diabetes management and support. Youth with T1D in Rwanda have barriers due to lack of immediate diabetes education, access to care, social support, employment and food security. Also, from the data used to create the LFAC/RDA registry, among these youth there is a need for improved follow-up and improvement of blood glucose levels. This proposal would be implemented with the youth identified for the LFAC/RDA registry (n = 181). The RDA has the baseline characteristics from previous clinical visits and can do a pre/post evaluation with the resulting outcomes for the assessment of peer support effectiveness.

##### *Identifying Peer Leaders*

Currently, the RDA has an informal peer support program that they have been developing for general diabetes, inclusive of all types. The program includes pairs of individuals living with diabetes that visit hospitals to speak with newly diagnosed patients. These individuals instruct on diabetes education and management. For the implementation of this current proposal of a formal



PSN for youth with T1D, the RDA could consider drawing from these already identified leaders if they are youth with Type 1 diabetes.

Peer Leaders have to be role models among the youth with T1D for diabetes management. Criteria for these individuals include having a diabetes management plan that they have followed successfully for a predetermined period of time, demonstrated responsibility and leadership skills, willing to make this level of social obligation, attentive listeners, and committed to the vision of connecting youth to care through providing social support. In addition, peer leaders would need to have excellent communication skills and demonstrate a level of literacy for conducting educational sessions. Through the peer leaders' own experiences with living with diabetes and navigating diabetes management, it is essential that peer leaders have respect for their peers as these individuals learn and adapt to their own lives with diabetes.

### *Training Peer Leaders*

Trainings for Peer Leaders would span four days of orientation and training would take place at the RDA or other community location in Kigali. RDA staff, other medical professionals trained in diabetes care, and youth who are highly competent and knowledgeable in diabetes care will be asked to train the first generation of peer leaders. In addition, the RDA and TDYA have training resources that they have used in training health professionals. Some of these resources have been supplied from international organizations through previous funding and projects. Initial funding and requests for these materials can be made for establishing a pilot group of peer leaders. These training modules would include diabetes education, diabetes management, counseling methods, stigma reduction, and ethics (See Table 3). Peer Leaders will also be trained in connecting with clinical staff and being a visible but unobtrusive presence in clinical/hospital

settings. Some nursing staff at a few hospitals have already indicated interest in acting as liaisons between the hospital and peer leaders. This would be useful in communicating to the peer leader when a new patient is diagnosed and needs assistance. Included in the training modules would be sessions to familiarize the Peer Leaders with diabetes education materials and teach how to teach. In order to ensure the trainings accomplish their goal, the peer leaders will take knowledge assessments as well as evaluate the training modules for efficiency and clarity. Additional trainings will be ongoing as new topics of interest may emerge and new leaders may be identified.

**Table 3. Peer Leader Training Sessions**

<b>Type of Training</b>	<b>Contents</b>	<b>Duration</b>	<b>Actions</b>
Diabetes Education	<ul style="list-style-type: none"> <li>• Dispelling Myths</li> <li>• Describing the diagnosis</li> <li>• Prevalence/Incidence</li> </ul>	4 hours	<ul style="list-style-type: none"> <li>• Providing learning materials</li> <li>• Holding individual sessions at diagnosis and as needed for the first month</li> <li>• Holding 1-hour in-person group education sessions on a monthly basis</li> </ul>
Diabetes Management	<ul style="list-style-type: none"> <li>• Insulin Regimens</li> <li>• Blood Glucose Monitoring</li> <li>• Nutrition and food security</li> <li>• Physical Activity</li> </ul>	4 hours	<ul style="list-style-type: none"> <li>• Holding individual sessions at diagnosis</li> <li>• Holding 1-hour in-person group education sessions discussing ideal maintenance for each point</li> <li>• Demonstrating proper testing</li> <li>• Taking quarterly food access assessments from the peers</li> <li>• Work with clinical staff for medicine distribution</li> </ul>
Counseling	<ul style="list-style-type: none"> <li>• Motivational Interviewing (MI) strategies with open-ended questions</li> <li>• Active listening</li> <li>• Journaling</li> <li>• Coping strategies</li> <li>• Identifying and Promoting factors for behavior change</li> <li>• Establishing boundaries</li> </ul>	4 hours	<ul style="list-style-type: none"> <li>• Holding one-on-one sessions with peers refreshing on diabetes education and management. If needed changes, use MI and active listening to engage and promote behavior change</li> <li>• Briefly documenting interactions with peers in a log book for every interaction</li> <li>• Weekly or more frequently, journal about topics discussed with peers and peer group</li> </ul>
Stigma Reduction	<ul style="list-style-type: none"> <li>• How to recognize stigma</li> <li>• How to discuss stigma with various groups of people</li> <li>• How to overcome stigma</li> </ul>	3 hours	<ul style="list-style-type: none"> <li>• Conduct stigma learning sessions during one-hour in-person sessions, every 6 months and as needed</li> <li>• Discuss peer encounters with stigma</li> </ul>
Confidentiality	<ul style="list-style-type: none"> <li>• Ethics of counseling</li> <li>• Non-disclosure</li> <li>• Reporting/referrals of health and social problems</li> </ul>	1 hour	<ul style="list-style-type: none"> <li>• Keep protected information confidential</li> <li>• Inform peer of confidentiality and about data for the project</li> </ul>
Teaching	<ul style="list-style-type: none"> <li>• Different learning styles</li> <li>• Types of learning materials</li> <li>• Designing learning materials</li> </ul>	2 hours	<ul style="list-style-type: none"> <li>• Develop new learning materials specific to group needs</li> <li>• Report successes and challenges among peer leader group weekly</li> </ul>

### *Peer Group Distribution*

This network will first be implemented in the capital, Kigali, Rwanda. The youth eligible for the LFA/RDA registry (n = 181) will be the group included for the PSN implementation. Based on the previously reviewed studies on peer support for diabetes management, the groups should not go over 10 people. However, the distribution between the three districts in Kigali (Gasabo, Kicukiro, and Nyagugenge) is uneven with the majority in Gasabo (n=53). To accommodate location while also providing a reasonable number to each peer leader, the peer support group will range between 7 and 8 peer members including the leader. Gasabo would ideally identify nine peer leaders and each leader would have six peer group members. Kicukiro (n=37) would need six peer leaders and each peer leader would have six to seven peer group members. Nyarugenge (n=44) would need five peer leaders and each peer leader would have seven group members. There are also the 43 non-residents who would need to be incorporated into these groups as well depending on their more convenience to Kigali province. They could be added to the Kigali groups until the group total reached ten.

This size should also accommodate for new members but overall this structure can be re-evaluated once the network is underway. In addition to their own groups, Peer Leaders will be also be a group among themselves and will be responsible for communicating across Kigali districts. From this break down, the PSN will need to identify 21 leaders for Kigali. Or, the additional provinces represented can each have one peer leader for every 4 – 5 RDA youth. The smaller range is due to the provinces being more spread out than Kigali. The North province will need two peer leaders; the South province will need five peer leaders; the East province will need one to two peer leaders depending on what they prefer; and the West province will need three peer leaders.

### *Peer Support Network Aims*

The following seven key areas were chosen based on stakeholder input and clinical findings on the RDA youth.

- i. Emotional support: Receiving the news of a T1D diagnosis is life changing; however, through the PSN, there is support available. The Peer Leaders have all been in this position before and understand the level of emotion occurring. Each newly diagnosed youth will immediately have a network of people who understand what it is like living with diabetes, and who have adapted and excelled in their life. As mentioned by the TDYA, having role models would be helpful in feeling hopeful and less distressed about living with T1D.
- ii. Financial support: Part of participating in the PSN is possibly, though not required, contributing to a fund for a peer group member in need or for a project peers want to take on. Financial need could be losing a job suddenly, having an unexpected health cost, or wanting to return to school or vocational training. Funding would be open to everyone and there would be a regulatory system in place for monitoring and tracking how the funds are distributed.
- iii. Medical distribution/ care access: Widely discussed by RDA staff and the TDYA, the lack of resources, particularly medication, was a barrier in maintaining ideal diabetes care. This is especially the case in the rural areas. Peer leaders will be responsible for working with the RDA to determine the best means of distributing medicine to the more rural areas or those who for other reasons cannot make frequent visits to the clinic. This will be supported through the intertwined communication network present throughout each peer support group. Peer support groups can facilitate the communication of medical needs.

- iv. Education/diabetes management: this is an essential component to the PSN as one of the key areas identified by stakeholders was the lack of education at the initial diagnosis. Receiving education and information on diabetes management at this time can be daunting for the youth. All at once, it's a lot of information to take in. As previously discussed, besides education healthcare professionals should work on dispelling myths of diabetes. Peer support leaders can really access this level of education because they have demonstrated a working knowledge of diabetes management and control. Peer Leaders teach not only through their lessons but also through their example.
- v. Follow up encouragement/facilitation: Feeling included and understood will encourage youth follow-up and participation in clinical and social activities. This has been discussed previously on the application of peer support to create and improve social relationships.
- vi. Reduce "Lost to Follow-Up": The goal of the peer support network is the reduction in lost to follow up from 12% to less than 5%. This is essential, especially given the population largely affected by T1D are children as well as young adults. Losing track of children is unacceptable and increased efforts should be made to ensure knowledge is always up-to-date on their whereabouts.
- vii. Advocacy: Many stakeholders discussed previous experiences with job discrimination and stigma in general. Part of the PSN will be to raise awareness of T1D and the quality of life those diagnosed with T1D can have. This could include hosting educational events to the general public, speaking at government forums, and traveling to conferences to promote research and international advocacy for those living with T1D.

#### 4.4.1 Data Collection

In a formal evaluation of the PSN, if funded and appropriately approved, I would propose collecting data concerning clinical measures obtained during the quarterly clinic visits already conducted by the RDA. During these visits, youths have their height, weight, blood pressure, random blood glucose, and HbA1c level measured. These measures are taken by trained professionals at every visit. Glycemic goal recommendations are to have HbA1c at less than 7.5% for children and adolescents (American Diabetes Association, 2019). In addition, the ADA recommends for providers to aim for HbA1c at < 6.5% if there is no indication of the patient having high hypoglycemia risk or any other adverse effects and <8% for those at potentially higher risk of ill-effect e.g. the elderly (Chamberlain et al., 2017). During the patient's more comprehensive annual visit, there are additional measures taken such as current education level, marital status, employment status as well as the occurrence of diabetes-related complications and number of hospitalizations.

Additional tools I would propose be used would be the Starr County Diabetes Knowledge Questionnaire (DKQ) and the Michigan Diabetes Knowledge Test (DKT). These two specific tests are proposed due to the previous applications and analyses on their outcomes for improved diabetes management. The Michigan Diabetes Research and Training Center's brief DKT was used in relevant context by Noorani et al. (2016) in measuring glycemic control among youth with T1D in Dar es Salaam, Tanzania. The DKT used in their study was a multiple-choice questionnaire modified, translated, and back translated into Kiswahili. A total of 14 questions out of the 23 item questionnaire were used: nine questions were omitted due to no relevance to the study population (Noorani, Ramaiya, & Manji, 2016). The results of the test were scored based on percentage of correct responses; however, this was a cross sectional study, so there was no change in knowledge

over time assessment. The DKQ is also proposed due to findings from a systematic review of three diabetes education assessments (Dawson, Walker, & Egede, 2017). The DKQ had the highest internal validity when compared to the DKT and a third assessment, the Kaiser DISTANCE. Of the three, the DKQ was the only assessment to have a significant correlation between diabetes knowledge and glycemic control (Dawson et al., 2017). However, both are proposed because the DKT has been used specifically for T1D and in a part of the sub-Saharan Africa region, the DKQ has stronger correlation with diabetes control although the systematic review does not demonstrate findings among youth with T1D or in a similar region to Rwanda. Both questionnaires would be translated in to Kinyarwanda and back translated by an independent source. Before use in the PSN evaluation, they would be piloted in individuals with T1D who are not eligible for the registry.

While the above mostly measure knowledge, there is also the Diabetes Quality of Life (DQoL) tool, which has been previously used among adolescents in Rwanda by the RDA and the University of Pittsburgh to assess quality of life among persons living with diabetes. The Diabetes Control and Complications Trial (DCCT) Research Group developed the DQoL instrument. The original tool contained 46 items used to measure health-related quality of life among diabetes patients based on three main domains, namely, “satisfaction,” “impact,” and “worry.” In the DCCT sample, reliability values ranged from .66 to .92 and test-retest reliabilities ranged from .78 to .92, with reliability of “worry” being low (Ingersoll & Marrero, 1991). The assessment was also originally tested on a sample of adults, adolescents less than 13 were excluded; however, the tool did include questions targeted to adolescents and the tool has been adapted for specific use with older children and adolescents (Ingersoll and Marrero, 1991). The revised instrument for adolescents had a 17-item Diabetes Life Satisfaction scale, a 26-item Disease Impact scale, and a



13-item Disease-Related Worries scale, also included was a general self-rating of overall health (Ingersoll and Marrero, 1991).

In addition, measuring perceptions of social support among youth with T1D is essential for assessing the impact of the PSN. The Medical Outcomes Study - Social Support Survey (MOS-SSS) contains 19 items used to measure five dimensions of social support: (1) emotional support (the expression of positive affect, empathetic understanding, and the encouragement of expressions of feelings), (2) informational support (the offering of advice, information, guidance or feedback), (3) tangible support (the provision of material aid or behavioral assistance), (4) positive social interaction (the availability of other persons to do fun things with you), and (5) affectionate support (involving expressions of love and affection) (Sherbourne & Stewart, 1991). Based on their results, the emotional and informational dimensions were highly correlated so were subsequently combined into one social support scale. As Sherbourne and Stewart (1991) suggest, while all the scales were found to have sufficient reliability, all one-year stability coefficients greater than 0.71, there is still a need to distinguish between structural social support versus functional social support. The support subscales for the MOS-SSS should be scored and separately assessed using the support subscales (Sherbourne and Stewart, 1991).

#### **4.4.2 Outcome Measures**

##### *Primary Outcomes*

HbA1c: With the majority (57.8%) of current youth in the registry having a HbA1c level of greater than 9%, post measures after implementing peer support would desire a decrease HbA1c levels for this group. The target HbA1c level for this population is 7.5%.

Systolic and Diastolic Blood Pressure: There have been reports that among youth at the RDA, there has been a rise in prevalence of hypertension (Marshall et al., 2015). While psychosocial stress has been linked to cardiovascular disease (Hackett & Steptoe, 2016), by which those with diabetes are largely affected, there is also support for psychosocial stress causing hypertension (Liu, Li, Li, & Khan, 2017). However, Liu et al. do conclude that psychosocial factors have a range of measures and the direct reason for the association to hypertension Liu et al. observed warrants further research. That being said, peer support programs have been shown to relieve diabetic distress and improve general well-being among adults with Type 2 diabetes (Ju et al., 2018). This outcome of reducing the prevalence of hypertension among the RDA youth is not unrealistic. The target range is to have systolic blood pressure at less than 120mmHg and diastolic blood pressure at less than 80mmHg. According to Marshall et al. (2015), 30.8% of youths were hypertensive from the 2012 RDA data. The outcome post this proposed PSN implementation would be to reduce hypertension towards the reported 15.3% found at the national level (Nahimana et al., 2017).

Diabetes Knowledge Assessments: to gauge if there is an increase in diabetes knowledge between initial diagnosis and diabetes knowledge assessed at the end of the PSN evaluation period (proposed as 18 months) scores from the chosen knowledge assessment will be compared.

### *Secondary Outcomes*

Body Mass Index (BMI): This would be assessed through the height and weight clinical measures taken during the quarterly clinic visits to the RDA. Currently, while staff are consistent in taking these measures, there should be improvements in accurately matching the data to the correct patient ID and recording the information every time at every visit.

Occurrence of Diabetes-Related Complications: These include number of times hospitalized, number of instances of ketoacidosis, occurrence of hyperglycemia, and occurrence of hypoglycemia.

Amount of Contact with Peer Leader: Peer leaders will keep a log of their contact with each peer group member. This log will show topic, estimate of duration of interaction, any problems, and updated contact information for the peer member. A sample of the logs will be deidentified, coded and analyzed for common themes to better understand the needs of the peers and to evaluate the process measure of peer leader and peer interactions.

Amount of Contact with Peer Group: This will be for the peer group member and is the number of times the member attends meetings or events with the entire peer group. This is another process measure to ensure that there is interaction occurring between the peers and the peer support groups. If a peer group member misses a session without notice, then the peer leader will reach out to that individual for a one-on-one session. If contact cannot be established, then the peer leader will reach out to the social network for reaching the peer group member.

Topics discussed with Peer Leader: Themes will be extracted from the Peer Leader Logs to identify common themes discussed between peer members and peer leaders. These themes will provide a qualitative outcome on areas of interest for youth with Type 1 Diabetes. They will also provide future directions for additional peer leader trainings and targeted programming for the youth.

Depression Scale: Compared to baseline, the depression scale will show whether or not there was change in depression due to participation with the peer support network.

Financial security: During their annual clinic visits to the RDA, youth are asked about their level of education and employment. Examining the sense of financial security would be beneficial given the degree of stress finances were reported by the TDYA to cause. While the program would

collect this data, the peer support network would also work to address this need for the individual. For this reason, data would be collected on the impact of the financial assistance provided by the PSN to the individual at various points in time post-assistance.

## **5.0 DISCUSSION**

### **5.1 IDENTIFIED FACILITATORS**

Throughout the design of this proposal, identifying potential facilitators is crucial to the future implementation of this peer support network in Kigali, Rwanda. One such facilitator is the RDA through their established relationship in the diabetes community. Another facilitator is the TDYA in their youth-led efforts towards formal government recognition. There continue to be collaborative discussions between Rwanda and members of the TDYA which fosters goodwill between the two countries.

Current Rwanda government initiatives also support the implementation of a peer support network. Over the last decade, Rwanda has made a large push to address the rising concern of non-communicable diseases as described in their publicly available strategic plans and demonstrated through their expansion of non-communicable disease clinics. The Rwanda government is also supporting more projects that improve data collection for non-communicable diseases specifically a project is being funded for the surveillance of T1D at the Rwanda Biomedical Center (RBC). Many stakeholders want improved means for collecting and standardizing data. The addition of a peer support network would complement the government level efforts of improved access to healthcare and data collection. Peer support is an efficient, cost effective, low-maintenance method for addressing this rapid increase in chronic diseases in Rwanda.

Clinical staff and additional healthcare professionals would also be facilitators in implementing the PSN. A lot of hospital staff face constraints when it comes to giving sufficient time to their patients. An established relationship with a peer leader could help alleviate that

burden. Peer leaders can be on-site or easily connected to patients recently diagnosed with T1D. The strength of adding peer support, in particular the peer leader, to diabetes care is that this creates an expert whose sole position is to immediately engage and facilitate educational conversations with newly diagnosed youth while providing that crucial emotional support. Clinical staff can know that this person is there and will give the emotional and social support the patient needs especially at the beginning of this life change. At a larger level, peer support has also shown reduction in healthcare costs, which could be due to addressing the psychosocial factors of disease through the support from the group. Youth have greater diabetes knowledge and improved communication for reporting issues in diabetes management right away thus preventing the development of diabetes related complications.

## **5.2 POTENTIAL BARRIERS/LIMITATIONS**

Designing an effective and sustainable peer support network is the goal of this proposal for youth with T1D in Rwanda. When considering the long-term maintenance of this program, something to examine is the consistent motivation of the peer leaders. One barrier to the project is establishing sufficient means for the peer leaders to stay involved. There has been some discussion around promoting a “true volunteer” as a peer leader versus the peer leader being a compensated role. Compensation does affect the sustainability of the program because if funding were to end, then the role would end. By implementing this program with the role as a volunteer position, the peer leaders are involved solely based on their personal desire to be involved. However, considering the demands of the role, there have to be other ways to promote the support of peer leaders. This could be through professional development, support in advanced education, or support for

attending project related activities such as meetings with other youth programs, conferences, or advocacy events. Firmly establishing realistic means of supporting ongoing roles in the peer support network is a barrier to consider because funding requirements have an effect on the sustainability of a project.

Overcoming stigma and promoting visibility of an organization in various settings are other components to consider when establishing a new program. While this paper did previously discuss the timeliness of peer support within the context of Rwanda's advances in addressing non-communicable disease care, there are still barriers to overcome in the perception of diabetes at the local and international levels. At the local level, education for healthcare professionals is still in progress, but there also needs to be an increase in efforts to raise diabetes awareness for the non-healthcare professional. One idea to raise awareness on the relevance of diabetes in a community is to hold informational meetings at schools. Some organizations are already working on these sessions. Education is so essential but sometimes teachers and academic administrators do not know how to provide services to youth with diabetes, especially T1D. The RDA also promotes community awareness of diabetes through their youth camps. In addition, peer leaders and peer groups can participate in events and trainings that discuss how to talk about diabetes. Stigma stems from a lack of understanding and fear. Increasing knowledge and awareness of a disease or social element can help towards eliminating that stigma.

Another potential barrier is the immediate accessibility for all youth with T1D in Rwanda to the peer support network. For the pilot program, the peer support network will be based in Kigali, the capital of Rwanda. This is an urban environment and implementation methods will be based on the resources available in this environment. While the intent is to disseminate the peer support network across the country, the majority of Rwanda is rural with additional limitations.

To assist in this barrier, the RDA already does have experience working in rural areas. In addition, there is already an informal network of stakeholders that could assist in developing rural access. Also, by having an established program set-up in Kigali, resolutions to general implementation set-backs will be known, which means implementation in more rural settings can focus efforts on overcoming issues specific to the rural areas. They will have the support of an already experienced group of peer leaders and youths. For materials, communication for these areas is crucial. One proposed element is providing phones to all leaders and having the peer support network incorporate a mobile health aspect to maintain more consistent connections between peer groups. Educational materials will also need to be modified to include any additional languages or cultural norms used in other parts of the country. As previously discussed, peer support is a culturally adaptable and flexible program that can meet a variety of needs. This project has to be sure it targets and can maintain meeting the needs of the diverse groups in Rwanda.

Data collection is a current limitation for this paper. Baseline measures from previously collected data were difficult to assess due to mismatched IDs and lack of records. However, the RDA has been promoting updating their efforts and protocols for data collection which could help alleviate these concerns. Data collection and data storage is an issue for many LMICs. With proper approvals and funding, this project will collect more recent data on the registry youth as the updated baseline measures. Through this more structured formal environment, having reliable and consistent data collection would be incorporated into implementation efforts.



## 6.0 CONCLUSION

Peer Support is a means for addressing many areas of concern for non-communicable diseases including diabetes in low to middle income countries where resources may be lacking. However, there are not specific formally established peer support programs currently present in Rwanda for diabetes care. Given the lack of social support post-diagnosis, limited access to medication, and poor diabetes education and self-management, improved holistic means of care are needed.

This proposal for implementing a peer support program in Kigali, Rwanda discusses how peer support can be culturally adapted to fit the needs of the diabetic community. The proposal also includes essential means for evaluating the program and ensuring it can make a sustainable contribution in the care of T1DY.

In addition, with growing awareness and support for peer support in chronic disease across East Africa, these programs can advocate for a unifying collaboration across countries. There are groups in Tanzania, Uganda, and Kenya that are advocating for addressing chronic/non-communicable disease issues now through diverse methods, not only addressing the clinical health outcomes but the social outcomes as well. Implementing a program in Rwanda would encourage the international collaboration and promote the local advances and abilities in diabetes care.

## BIBLIOGRAPHY

- Afadhali, J.-P. (2017). Rwanda's health centres to get NCD clinics by June. Retrieved March 30, 2019, from The East African website: <https://www.theeastafrican.co.ke/rwanda/News/Health-centres-to-get-NCD-clinics-by-June/1433218-4245448-lhm2yf/index.html>
- American Diabetes Association. (2019). Standards of Medical Care in Diabetes - 2019 Abridged for Primary Care Providers. *Clinical Diabetes*, 37(1). <https://doi.org/10.2337/dc13-S011>
- Assah, F. K., Atanga, E. N., Enoru, S., Sobngwi, E., & Mbanya, J. C. (2015). Community-based peer support significantly improves metabolic control in people with Type 2 diabetes in Yaoundé, Cameroon. *Diabetic Medicine*, 32(7), 886–889. <https://doi.org/10.1111/dme.12720>
- Atun, R., Davies, J. I., Gale, E. A. M., Bärnighausen, T., Beran, D., Kengne, A. P., ... Werfalli, M. (2017). Diabetes in sub-Saharan Africa: from clinical care to health policy. *The Lancet Diabetes and Endocrinology*. [https://doi.org/10.1016/S2213-8587\(17\)30181-X](https://doi.org/10.1016/S2213-8587(17)30181-X)
- Atun, R., & Gale, E. A. M. (2015). The challenge of diabetes in sub-Saharan Africa. *The Lancet Diabetes and Endocrinology*. [https://doi.org/10.1016/S2213-8587\(15\)00236-3](https://doi.org/10.1016/S2213-8587(15)00236-3)
- Baumann, L. C., Josphine, E., Agatha, N., Frederick, N., & Betty, N. (2014). A Demonstration of Peer Support for Ugandan Adults With Type 2 Diabetes. *International Journal of Behavioral Medicine*. <https://doi.org/10.1007/s12529-014-9412-8>
- Beran, D., Ewen, M., & Laing, R. (2016). Constraints and challenges in access to insulin: A global perspective. *The Lancet Diabetes and Endocrinology*, 4(3), 275–285. [https://doi.org/10.1016/S2213-8587\(15\)00521-5](https://doi.org/10.1016/S2213-8587(15)00521-5)
- Binagwaho, A., Farmer, P. E., Nsanzimana, S., Karema, C., Gasana, M., De Dieu Ngirabega, J., ... Drobac, P. C. (2014). Public Health Rwanda 20 years on: investing in life. *The Lancet*, 384, 371–375. [https://doi.org/10.1016/S0140-6736\(14\)60574-2](https://doi.org/10.1016/S0140-6736(14)60574-2)
- Boothroyd, R. I., & Fisher, E. B. (2010). Peers for progress: promoting peer support for health around the world. *Family Practice*. <https://doi.org/10.1093/fampra/cmq017>
- Boutayeb, A. (2006). The double burden of communicable and non-communicable diseases in developing countries. *Transactions of the Royal Society of Tropical Medicine and Hygiene*. <https://doi.org/10.1016/j.trstmh.2005.07.021>
- Chamberlain, J. J., Kalyani, R. R., Leal, S., Rhinehart, A. S., Shubrook, J. H., Skolnik, N., & Herman, W. H. (2017). Treatment of type 1 diabetes: Synopsis of the 2017 American Diabetes Association standards of medical care in diabetes. *Annals of Internal Medicine*. <https://doi.org/10.7326/M17-1259>

- Cheng, S., Kamano, J., Kirui, N. K., Manuthu, E., Buckwalter, V., Ouma, K., & Pastakia, S. D. (2013). Prevalence of food insecurity in patients with diabetes in western Kenya. *Diabetic Medicine*, 30(6), e215–e222. <https://doi.org/10.1111/dme.12174>
- Dawson, A. Z., Walker, R. J., & Egede, L. E. (2017). Differential Relationships Between Diabetes Knowledge Scales and Diabetes Outcomes. *Diabetes Educator*, 43(4), 360–366. <https://doi.org/10.1177/0145721717713316>
- Debussche, X., Besançon, S., Balcou-Debussche, M., Ferdynus, C., Delisle, H., Huiart, L., & Sidibe, A. T. (2018). Structured peer-led diabetes self-management and support in a low-income country: The ST2EP randomised controlled trial in Mali. *PLoS ONE*. <https://doi.org/10.1371/journal.pone.0191262>
- Dennis, C.-L. (2003). Peer support within a health care context: a concept analysis. In *International Journal of Nursing Studies* (Vol. 40).
- Fisher, E. B., Coufal, M. M., Parada, H., Robinette, J. B., Tang, P., Urlaub, D., ... Xu, C. (2014). Peer Support in Health Care and Prevention: Cultural, Organizational, and Dissemination Issues. In *SSRN*. <https://doi.org/10.1146/annurev-publhealth-032013-182450>
- Fisher, E. B., Earp, J. A., Maman, S., & Zolotor, A. (2010). Cross-cultural and international adaptation of peer support for diabetes management. *Family Practice*. <https://doi.org/10.1093/fampra/cmp013>
- Hackett, R. A., & Steptoe, A. (2016). Psychosocial Factors in Diabetes and Cardiovascular Risk. *Current Cardiology Reports*. <https://doi.org/10.1007/s11886-016-0771-4>
- Ingersoll, G. M., & Marrero, D. G. (1991). *A Modified Quality-of-Life Measure for Youths: Psychometric Properties*. Retrieved from <https://journals-sagepub-com.pitt.idm.oclc.org/doi/pdf/10.1177/014572179101700219>
- Ju, C., Shi, R., Yao, L., Ye, X., Jia, M., Han, J., ... Sun, Z. (2018). Effect of peer support on diabetes distress: a cluster randomized controlled trial. *Diabetic Medicine*, 35(6), 770–775. <https://doi.org/10.1111/dme.13625>
- Langston, A., Weiss, J., Landegger, J., Pullum, T., Morrow, M., Kabadege, M., ... Sarriot, E. (2014). Plausible role for CHW peer support groups in increasing care-seeking in an integrated community case management project in Rwanda: a mixed methods evaluation. *Global Health, Science and Practice*, 2(3), 342–354. <https://doi.org/10.9745/GHSP-D-14-00067>
- Liu, M. Y., Li, N., Li, W. A., & Khan, H. (2017). Association between psychosocial stress and hypertension: a systematic review and meta-analysis. *Neurological Research*, 39(6), 573–580. <https://doi.org/10.1080/01616412.2017.1317904>

- Makani, J., Matuja, W., Liyombo, E., Snow, R. W., Marsh, K., & Warrell, D. A. (2003). Admission diagnosis of cerebral malaria in adults in an endemic area of Tanzania: Implications and clinical description. *QJM - Monthly Journal of the Association of Physicians*, *96*(5), 355–362. <https://doi.org/10.1093/qjmed/hcg059>
- Marjerrison, S., Cummings, E. A., Glanville, N. T., Kirk, S. F. L., & Ledwell, M. (2011). Prevalence and Associations of Food Insecurity in Children with Diabetes Mellitus. *The Journal of Pediatrics*, *158*, 607–611. <https://doi.org/10.1016/j.jpeds.2010.10.003>
- Marshall, S. L., Edidin, D., Arena, V. C., Becker, D. J., Bunker, C. H., Gishoma, C., ... Orchard, T. J. (2015). GLUCOSE CONTROL IN RWANDAN YOUTH WITH TYPE 1 DIABETES FOLLOWING ESTABLISHMENT OF SYSTEMATIC, HBA1C BASED, CARE AND EDUCATION. *Diabetes Res Clin Pract*, *107*(1), 113–122. <https://doi.org/10.1016/j.diabres.2014.09.045>
- Marshall, S. L., Edidin, D., Arena, V. C., Becker, D. J., Bunker, C. H., Gishoma, C., ... Orchard, T. J. (2015). Prevalence and incidence of clinically recognized cases of Type 1 diabetes in children and adolescents in Rwanda, Africa. *Diabetic Medicine*, *32*(9), 1186–1192. <https://doi.org/10.1111/dme.12701>
- Mendoza, J. A., Haaland, W., D'agostino, R. B., Martini, L., Pihoker, C., Frongillo, E. A., ... Liese, A. D. (2018). Food Insecurity is Associated with High Risk Glycemic Control and Higher Health Care Utilization among Youth and Young Adults with Type 1 Diabetes HHS Public Access. *Diabetes Res Clin Pract*, *138*, 128–137. <https://doi.org/10.1016/j.diabres.2018.01.035>
- Michielsen, K., Beauclair, R., Delva, W., Roelens, K., Van Rossem, R., & Temmerman, M. (2012). Effectiveness of a peer-led HIV prevention intervention in secondary schools in Rwanda: results from a non-randomized controlled trial. *BMC Public Health*, *12*, 729. <https://doi.org/10.1186/1471-2458-12-729>
- Mukeshimana, M. M., & Nkosi, Z. Z. (2014). Communities' knowledge and perceptions of type two diabetes mellitus in Rwanda: A questionnaire survey. *Journal of Clinical Nursing*. <https://doi.org/10.1111/jocn.12199>
- Nahimana, M. R., Nyandwi, A., Muhimpundu, M. A., Olu, O., Condo, J. U., Rusanganwa, A., ... Okeibunor, J. C. (2017). A population-based national estimate of the prevalence and risk factors associated with hypertension in Rwanda: Implications for prevention and control. *BMC Public Health*, *18*(1), 1–11. <https://doi.org/10.1186/s12889-017-4536-9>
- Noorani, M., Ramaiya, K., & Manji, K. (2016). Glycaemic control in type 1 diabetes mellitus among children and adolescents in a resource limited setting in Dar es Salaam- Tanzania. *BMC Endocrine Disorders*. <https://doi.org/10.1186/s12902-016-0113-y>
- Ogle, G. D., Middlehurst, A. C., & Silink, M. (2016). The IDF Life for a Child Program Index of diabetes care for children and youth. *Pediatric Diabetes*, *17*(5), 374–384. <https://doi.org/10.1111/pedi.12296>

- Ogle, G., Middlehurst, A., Silink, M., & Hanas, R. (2017). *Pocketbook for Management of Diabetes in Childhood and Adolescence in Under-Resourced Countries*. Retrieved from [www.idf.org/lifeforachild](http://www.idf.org/lifeforachild)
- Our Story – Rwanda Diabetes Association. (2019). Retrieved March 30, 2019, from <https://rwandadiabetes.com/our-story/>
- Rehfuess, E. A., Durão, S., Kyamanywa, P., Meerpohl, J. J., Young, T., & Rohwer, A. (2016). An approach for setting evidence-based and stakeholder-informed research priorities in low- and middle-income countries. *Bulletin of the World Health Organization*, 94(4), 297–305. <https://doi.org/10.2471/BLT.15.162966>
- Republic of Rwanda Noncommunicable Diseases Policy*. (2015). Retrieved from [www.moh.gov.rw](http://www.moh.gov.rw)
- Rowlands, A., Ameyaw, E., Rutagarama, F., Dipesalema, J., Majaliwa, E. S., Mbogo, J., ... Chanoine, J. P. (2018). Insights from the WHO and national lists of essential medicines: Focus on pediatric diabetes care in Africa. *Hormone Research in Paediatrics*. <https://doi.org/10.1159/000490467>
- Rwanda, N. I. of S. of. (2018). *Mortality Assessment Survey 2015*. Kigali.
- Sherbourne, C. D., & Stewart, A. L. (1991). The MOS Social Support Survey. *Soc. Sci. Med.*, 32(6), 705–714. Retrieved from <https://pdf.sciencedirectassets.com/271821/1-s2.0-S0277953600X02912/1-s2.0-027795369190150B/main.pdf?x-amz-security-token=AgoJb3JpZ2luX2VjEGMaCXVzLWVhc3QtMSJGMEQCIHvYQMzCdViuHY4V5vIz7EUs%2BZnNMbjJI67MG1SpLBD0AiBtGNiHWwU6sv3AFREYACRI90HvRGqSJCWHfcEhMh4N2yr>
- The IDF Diabetes Atlas, 8th Edition, Rwanda*. (2017). Retrieved from <https://reports.instantatlas.com/report/view/704ee0e6475b4af885051bcec15f0e2c/RWA>
- The IDF Diabetes Atlas, AFRICA Highlights*. (2017). Retrieved from [www.diabetesatlas.org](http://www.diabetesatlas.org)
- The IDF Diabetes Atlas*. (2017).
- You, W. P., & Henneberg, M. (2016). Type 1 diabetes prevalence increasing globally and regionally: The role of natural selection and life expectancy at birth. *BMJ Open Diabetes Research and Care*. <https://doi.org/10.1136/bmjdr-2015-000161>
- Zhong, X., Wang, Z., Fisher, E. B., & Tanasugarn, C. (2015). Peer support for diabetes management in primary care and community settings in Anhui Province, China. *Annals of Family Medicine*. <https://doi.org/10.1370/afm.1799>