



## Diabetes in Rural Rwanda: High Retention and Positive Outcomes after 24 Months of Follow-up in the Setting of Chronic Care Integration

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### Abstract

**Aims:** This study describes the baseline characteristics and 24 month outcomes of diabetic patients managed in an integrated chronic care program at public facilities in rural Rwanda.

**Methods:** Retrospective review of routine electronic medical records of patients treated for diabetes between October 1, 2006 and September 30, 2014 was conducted. Baseline demographic and clinical characteristics are described. Outcomes of HbA1c values, loss to follow-up and death are reported.

**Results:** Of 544 patients enrolled, 305 (56.1%) were female and twenty-two (4.0%) were younger than 18 years. Of those with adequate documentation, 72.3% were subsistence farmers, 35.8% had baseline BMI  $\geq$  25, and 5.3% were current smokers. Median HbA1c was 10.3% (IQR: 8.3, 11.9) at baseline and 8.2% (IQR: 6.3, 10.1) at seven to 12 months of follow-up. For 394 patients with at least 24 months between enrollment and study period end, 66 (16.8%) were lost-to-follow-up, 12 (3.0%) died within the first 24 months and 316 (80.2%) were alive and in care.

**Conclusions:** Our findings indicate that diabetes can be effectively managed with reasonable outcomes in a rural resource-limited setting. We also found relatively low lifestyle risk factors and comorbidities among our patients compared with those in the United States and Europe.

### Keywords

Diabetes, Sub-Saharan Africa, Nurse-led care, Task-shifting, Rwanda

### Introduction

The increasing burden of chronic non-communicable diseases (NCDs) around the world is particularly concerning in low- and middle-income countries (LMICs), where 80% of NCD-related deaths occur [1]. In 2008, diabetes affected 382 million adults worldwide [2] and accounted for 1.3 million deaths [1]. In sub-Saharan Africa, diabetes is predicted to rise rapidly, increasing by 80% over 20 years and affecting 18.7 million by the year 2025 [3]. Diabetes, however, is not just an emerging problem in this region; it has long been an endemic killer of the rural poor [4]. Diabetes also causes significant morbidity, increasing the risk of non-traumatic lower limb amputations by ten-fold [1], as a leading cause of renal failure [1,5,6] and visual impairment [1] and as a major risk factor for cardiovascular disease around the world [1,7].

Despite this, access to services for diabetes care in sub-Saharan Africa is limited and there are significant disparities in patient outcomes when compared with global statistics. In 2013, although only 8.6% of all deaths in sub-Saharan Africa were attributed to diabetes, 76.4% of these deaths occurred in people under the age of 60 years, compared to the 50% or less among diabetes-related deaths world-wide [2]. Access to services for rural patients is particularly lacking [8]. Contributing factors include few trained personnel, expensive medications and equipment [9], late presentation, delayed diagnosis, as well as treatment complications related to food insecurity such as hypoglycemia [3].

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Although literature provides several examples of diabetes programs in sub-Saharan Africa [6-16], few describe outcomes from programs based in rural settings in low-income countries where care is coordinated between secondary facilities, primary health centers and the community. Since 2006, Partners In Health (PIH)-an international non-governmental organization with a mandate to deliver healthcare to rural poor-has supported the Rwandan Ministry of Health (RMOH) in delivering care for diabetes and other NCDs at public facilities in rural districts through a strategy of progressive chronic care integration [17,18]. More complex outpatient services-such as insulin management and anticoagulation are delivered at district hospitals, by specialized nurses who also provide training, mentorship and supervision to health center staff. Chronic care at health centers is provided in a more integrated fashion, while community health workers contribute to adherence support and case finding for symptomatic patients. Here, we describe the diabetic population served and disease outcomes at these facilities, with a view of informing approaches to diabetes care delivery in similar settings.

## Methods

### Study setting

Although Rwanda has a gross national income of US\$630 per capita (2013) [19] and 70% of the rural population was living in multidimensional poverty in 2010 [20], the RMOH has made much progress in health and development by emphasizing equity and focusing on primary care and integration of services [21]. However, similar to other countries in the region, diabetes remains a significant problem. National records indicate that diabetes was among the top five causes of morbidity in the internal medicine department of a national referral hospital in Butare [22], and a study conducted at Rwanda's national teaching hospital in Kigali found significant morbidity and complications among admitted and ambulatory diabetes patients [15]. Access to diabetes services has been expanded through universal public health insurance coverage and outreach efforts by trained pediatric diabetes clinicians to some district hospitals [23]. However, gaps remain including weak monitoring and evaluation systems nationally [24], limited equipment for glucose and HbA1c testing, general lack of population awareness about diabetes [25] and too few facilities providing longitudinal services accessible to rural-based patients.

In Rwanda, PIH supports delivery of health services at public facilities in three rural districts, with a total catchment of 850,000 people. Southern Kayonza and Kirehe Districts are located in the Eastern Province, while Burera District is located in the Northern Province. NCD programs have been established at the three district hospitals and seven health centers (out of the 41 health centers within these three districts) and, as of June 2015, over 3,000 patients have been enrolled in the NCD program [18].

### Patient management

The model of comprehensive chronic care integration employed at PIH-supported public facilities in Rwanda is described in detail elsewhere [17,18,26]. For diabetes, nurses receive didactic and practical training on diagnosis and long-term management of diabetic patients that is complemented by long-term mentorship from physicians and specialist nurses. At the district hospitals, each NCD clinic is staffed with at least two trained RMOH nurses who cover the diabetes-specific clinic held once a week. Patients requiring admission are cared for by physicians and nurses in the pediatrics or internal medicine wards, in consultation by NCD clinic team. At each of the seven health centers with NCD clinics, two trained RMOH nurses take turns covering the weekly NCD clinic that includes diabetes but is not disease-specific. Health center NCD clinics receive visits from a district hospital NCD nurse at least once a month for continued mentorship, employing a structured mentorship model that has been established for women's health, HIV and other clinical spheres [27,28].

Diagnosis and monitoring employs point-of-care testing for urine

glucose, urine ketones, blood glucose and, for the district hospitals only, hemoglobin A1c (HbA1c). Additionally, tests routinely available at the facility's laboratory, such as renal function tests, are performed to support diagnosis and monitoring. Treatment includes individual counseling on lifestyle risk factor modification and group patient education sessions, oral hypoglycemic agents (glibenclamide, or metformin if BMI > 25.0), insulin (routinely available at the district hospital but only available for emergencies at the health center level) and socioeconomic supports such as food, transport vouchers and community health worker follow-up for vulnerable patients. Frequency of patient visits for clinical consultation ranges from weekly to every two months, depending on acuity of a patient's illness.

### Data collection and analysis

We conducted a retrospective review of routine electronic medical records (EMR) of patients managed for diabetes at PIH-supported public NCD programs between October 1, 2006 and September 30, 2014. Where electronic data were missing or ambiguous, manual chart abstraction was conducted. Patients who met the following criteria were excluded: missing date of enrollment, date of enrollment was prior to October 1, 2006 or later than September 30, 2014, and baseline HbA1c < 6.5.

We report number and frequency of patient demographic and clinical characteristics at baseline. Given the relatively recent (June 2012) establishment of the oncology component of EMR and resultant incomplete data entry, data related to cancer as a comorbidity were not included. We report outcomes of death, loss to follow-up and HbA1c value measured at follow-up milestones of 6 (defined as four to six months follow-up, inclusive), 12 (seven to 12 months follow-up), 18 (13 to 18 months follow-up) and 24 months (19 to 24 months follow-up). Loss to follow-up (LTFU) for a particular milestone was defined as patient's last visit occurring 3 months or more before the end of the milestone period. Data were administratively censored at September 30, 2014 and individuals who did not have enough months of follow-up were excluded from the reported outcomes for that follow-up milestone period. Differences between group HbA1c values at baseline and at 6, 12, 18 and 24 month follow-up milestones were assessed using Wilcoxon sign-rank tests at the  $\alpha = 0.05$  significance

**Table 1:** Baseline sociodemographic characteristics of diabetic patients managed at PIH-supported MOH NCD programs.

Characteristic	n	%
<b>Age</b>	<b>544</b>	<b>100.0</b>
< 18	22	4.0
18-30	68	12.5
30-45	136	25.0
46-60	214	39.3
> 60	104	19.1
<b>Gender</b>	<b>544</b>	<b>100.0</b>
Female	305	56.1
Male	239	43.9
<b>Marital status (if patient &gt; = 18 years)</b>	<b>375</b>	<b>100.0</b>
Single	37	9.9
Married or living with partner	272	72.5
Widowed or divorced	66	17.6
<b>Occupation</b>	<b>379</b>	<b>100.0</b>
Farmer	274	72.3
Employed (e.g. cleaner, professional) or Student	79	20.84
Retired	9	2.37
Unemployed	17	4.49
<b>Number of children (if patient &gt; = 18 years)</b>	<b>324</b>	<b>100.0</b>
up to 5 children	161	49.7
6-10 children	138	42.6
11 or more children	25	7.7
<b>Province of residence</b>	<b>544</b>	<b>100.0</b>
Eastern	428	78.7
Northern	108	19.9
Other	8	1.5

level. All analyses were conducted using Stata v12 (College Station, TX: StataCorp LP). The study received ethics approval from the Rwanda National Ethics Committee (Kigali, Rwanda) and the Partners Healthcare Research Committee (Boston, USA).

## Results

Of the 544 patients enrolled for diabetes care, 305 (56.1%) were female (Table 1). Twenty-two (4.0%) patients were younger than 18 years at enrollment, while 68 (12.5%), 350 (64.3%) and 104 (19.1%) were aged between 18-30 years, 31-60 years and over 60 years, respectively. Most patients (n = 272, 72.5% out of the 375 adults with documented marital status) were married and 163 (50.3% of the 324 adults with number of children documented) had six or more children. The majority of patients (n = 274, 72.3%, of the 379 adults with documented occupation status) were subsistence farmers. Nearly all patients (n = 536, 98.5%) resided in either Northern or Eastern Province and most were residents of the three PIH-supported districts (Figure 1).

For the 287 with type of diabetes documented, the majority (n = 248, 86.4%) had Type 2 diabetes (Table 2). A third (n = 133, 35.8%, of the 371 with documented baseline BMI) had baseline BMI of 25 or more and 52 (14.0%) had BMI less than 18. Only 22 (5.3% of the 418 with documented status) of diabetes patients were current smokers and 56 (13.9% of the 402 with documentation) currently consumed alcohol of any quantity. Only 53 (9.7%) patients had a documented chronic disease comorbidity: 28 with hypertension, 19 with HIV, three with asthma, two with heart failure and one with heart failure and asthma.

Of the 544 diabetes patients ever enrolled, 30 patients did not return following initial visit. For the 478 patients with at least 12 months between enrollment and the end of the study period, 55 (11.5%) patients were LTFU and eight (1.7%) died within the first 12 months (Table 3). The majority (n = 415, 86.8%) were alive and in-care at 12 months. For the 394 patients with at least 24 months between enrollment and the end of the study period, 66 (16.8%)

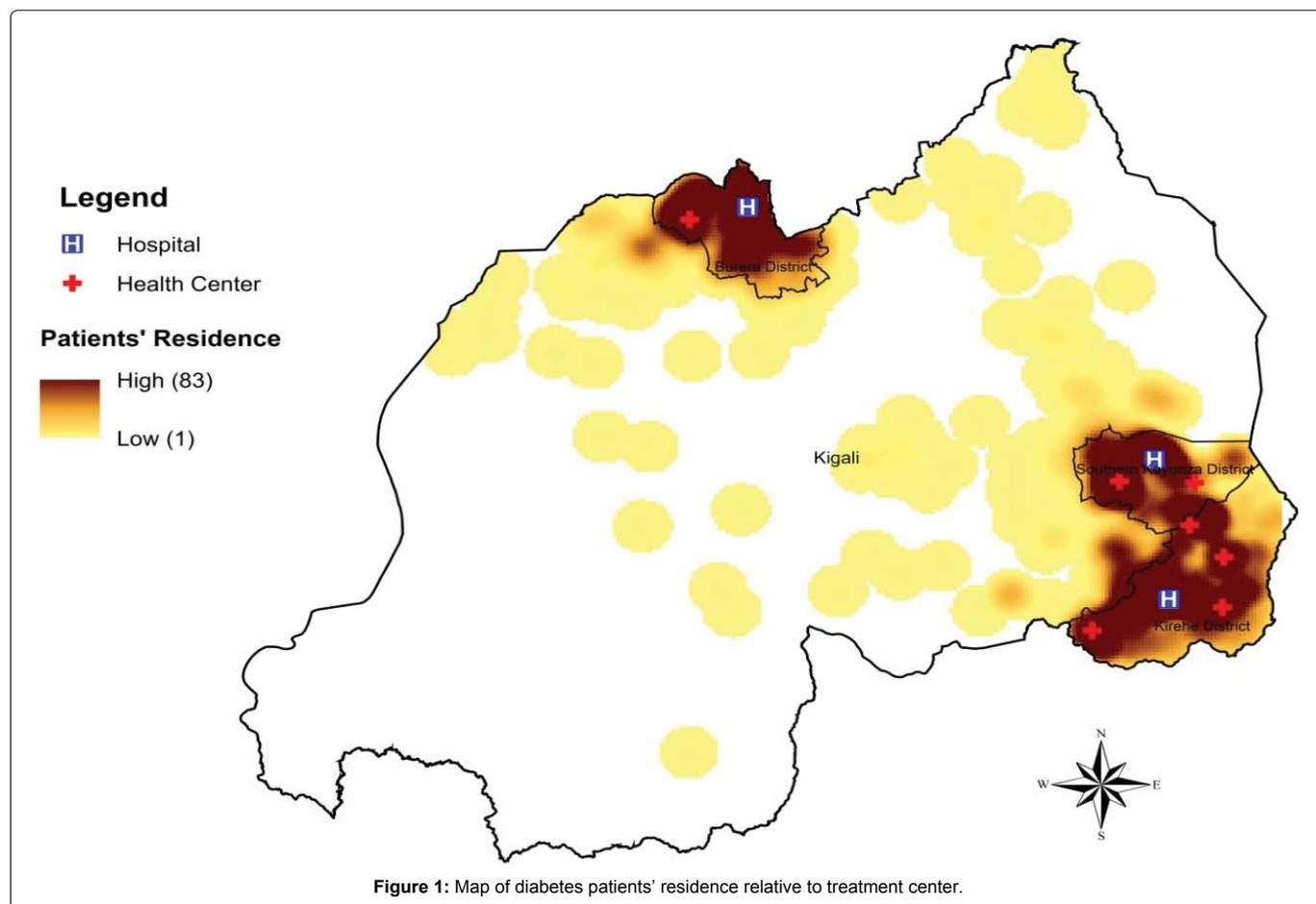
patients were LTFU and 12 (3.0%) died within the first 24 months and 316 (80.2%) of patients were alive and in-care at 24 months.

For the 70 patients with HbA1c test results documented at baseline (within three months of first visit), median baseline HbA1c was 10.3% DCCT (inter quartile range (IQR: 8.3, 11.9). At four to six months of follow-up, median HbA1c was 8.5% (IQR: 6.0, 11.0, N = 29). At seven to 12 months of follow-up, median HbA1c was 8.2% (IQR: 6.3, 10.1, n = 64). At 13 to 18 months follow-up, median HbA1c was 8.4% (IQR: 6.7, 9.4, n = 70). At 19 to 24 months follow-up, median HbA1c was 8.6% (IQR: 6.5, 10.2, n = 71). Among all patients

**Table 2:** Baseline clinical characteristics of diabetic patients managed at PIH-supported MOH NCD programs.

Characteristic	n	%
<b>Diabetes Type</b>	<b>287</b>	<b>100.0</b>
Type 1 diabetes	39	13.6
Type 2 diabetes	248	86.4
<b>BMI</b>	<b>371</b>	<b>100.0</b>
Underweight (BMI < 18.5)	52	14
Normal weight (18.5 ≥ BMI < 25)	186	50.1
Overweight (25 ≥ BMI < 30 )	80.0	21.6
Obese (BMI ≥ 30)	53	14.3
<b>Smoking history</b>	<b>418</b>	<b>100.0</b>
Currently	22	5.3
Past	98	23.4
Never	298	71.3
<b>Alcohol history</b>	<b>402</b>	<b>100.0</b>
Currently	56	13.9
Past	162	40.3
Never	184	45.8
<b>Chronic disease comorbidities*</b>	<b>544</b>	<b>100.0</b>
None (Diabetes only)	491	90.3
One additional diagnosis	52	9.6
Two additional diagnoses	1	0.2

\*Hypertension, heart failure, asthma, or HIV



**Figure 1:** Map of diabetes patients' residence relative to treatment center.

**Table 3:** Outcomes among diabetic patients followed at baseline and 6, 12, 18 and 24 months.

	Baseline		6 months		12 months		18 months		24 months	
<b>Number of patients with enough time between enrollment and study end to be included</b>	544		517		478		423		394	
<b>Alive and in care, by end of milestone (n,%)</b>	544	100%	475	91.9%	415	86.8%	357	84.4%	316	80.2%
<b>If Alive, No. with HbA1c tested</b>	70		29		57		64		64	
Median HbA1c (IQR)‡	10.3 (8.3-11.9)		8.5 (6.0-11.0)		8.2 (6.1-10.2)		8.4 (6.7-9.6)		8.6 (6.5-10.2)	
<b>If Alive, No. with HbA1c tested and baseline HbA1c &gt; 10</b>	38		4		9		5		2	
Median HbA1c (IQR)‡	12.0 (11.2-13.0)		8.2 (6.0-10.4)		8.1 (5.9-11.0)		9.3 (9.1-10.1)		7.7 (6.9-8.5)	
<b>Died, by end of milestone (out of those with sufficient follow up) (n,%)</b>	N/A		5	1.0%	8	1.7%	14	3.3%	12	3.0%
<b>Lost to follow up, by end of milestone (n,%)</b>	N/A		37	7.2%	55	11.5%	52	12.3%	66	16.8%

‡HbA1c measured in the following windows: baseline: 0-3 months; 6 months: 4-6 months; 12 months: 7-12 months; 18 months: 13-18 months; 24 months: 19-24 months

who had HbA1c results documented at both baseline and seven to 12 month time period (n = 16), median HbA1c was 10.9 (IQR: 7.8, 12.6) and 7.2 (IQR: 6.3, 11), respectively (p = 0.04). Among patients with baseline HbA1c > 10, nine had HbA1c documented at baseline and at 7 to 12 months follow up interval; median HbA1c was 12.2 (IQR: 11.6, 13) and 6.4 (IQR: 5.9, 11), respectively (p = 0.01).

## Discussion

Our findings indicate high 24-month retention rates for diabetes patients in a predominantly rural, poor population residing in a low-income country. Further, for patients who are enrolled and retained in the program, reasonable glycemic control has been achieved and maintained over a long time. The baseline HbA1c values seen among our patients are higher than those in patients in developed countries [29,30], and comparable to those in the region [6,10,23].

Few studies in the region report survival, retention or LTFU rates among diabetic patients. A descriptive study of diabetic and hypertensive patients from Cameroon reported a LTFU rate (defined as no visit for three or more months) of 70.6% with median follow up of 17.6 months [12]. Results from a cluster randomized trial of hypertensive and diabetic patients in rural Cameroon reported 29% retention at 12 months in the control arm, 60% retention in patients that received medication subsidies and 65% retention in patients that received missed visit reminder letters [31]. Our patient outcomes were considerably better than these two studies with 16.8% LTFU at twenty-four months. However, there remains room for improvement in patient retention. It is possible that relocation of patients to other facilities outside of the PIH catchment area, which was not routinely captured, inflated our LTFU rates and we recommend that this be better documented in the future. Further, the NCD program recently started active tracing of LTFU patients and determination of death using home visits by community health workers and contacting next of kin. This will help the program better understand the needs of patients LTFU for developing appropriate interventions.

While type of diabetes was missing for nearly half of our patients, 86% of those with documented type were type 2. Type 2 diabetes is estimated to comprise well over 90% of cases in Africa [32,33], which is comparable to 85% - 95% of diabetes cases in high income countries (HICs) [2]. Differences in characteristics between type 1 diabetes in low income and high income settings, such as later age of onset and distinct risk factors, may exist and have been suggested in studies in the region [33-37]. We did not have sufficient type 1 diabetes patient numbers to explore characteristics within this group. Our setting also does not allow for islet autoantibody and C-peptide testing that can evaluate for diagnosis of type 1 diabetes in patients where diagnosis type may be less clear (adolescents or young adults, obese) [38]. Starting in 2015, systematic evaluation with blood glucose testing of children and adolescents with symptoms suggestive of diabetes will be conducted at all health centers in Southern Kayonza District and characterization with C-peptide and islet autoantibody testing will be conducted for a subset of patients.

The World Health Organization (WHO) attributes NCD burden to four main lifestyle risk factors: unhealthy diet, lack of

physical activity, tobacco use, and harmful alcohol use [1,39]. Our patient population, predominantly rural based, does not have high proportions of the typical lifestyle risk factors of smoking, harmful alcohol use, sedentary lifestyle or obesity. The low proportion of overweight and obese individuals (36%) is consistent with findings of rural communities in other settings [40] but contrasts with 68% prevalence observed in the United States' general population in 2007-8 [41] and 94% prevalence observed among type 2 diabetics followed at secondary care clinics in the United Kingdom [42]. That nearly three quarters of patients with documented occupation are subsistence farmers also is an indication of relatively active lifestyle. Our findings are consistent with studies that have found that traditional risk factors for diabetes such as higher income, higher education level and urban living play a lesser role in settings of rural poverty [3,33,43]. Some headway has been made with population-based risk factor studies and national surveillance (World Health Organization STEP-wise Approach to Surveillance, Demographic and Health Survey), however, more data are needed to properly assess true burden of diabetes, assess risk factors and outcomes in LMICs [3,24].

## Limitations

Our study has some notable limitations. The retrospective design of the study and reliance on routinely collected electronic health data limited data availability. A likely cause of missing data related to HbA1c is the evolving system of health information collection. Early in the program clinical forms for diabetes did not have a specific field for recording HbA1c, so clinicians either left this undocumented or annotated the paper chart. Since December 2011, a specific HbA1c field was added to both paper and electronic forms to preclude this paper and electronic chart inconsistency. However, even with this contribution to missing data, it was evident that many patients did not receive HbA1c testing according to protocol, which specifies that all patients should have at least one HbA1c check per year and more frequently for those whose medications are being actively titrated. Reasons for suboptimal testing include stock-out of test cartridges, clinicians' inability to perform the point-of-care test due to high clinic patient volume or not realizing that patient is due for routine test. In the future, we plan to optimize HbA1c procurement systems by increasing threshold stock volumes that trigger new stock to be ordered, so that there is more lead time before stock outs occur. Furthermore, additional staff has been hired to support the needs of growing patient numbers and the electronic medical records system is being used to generate alerts when patients are due for HbA1c testing.

Given limitations on medication details in the EMR, we were not able to exclude patients who were already on treatment at time of enrollment. Inclusion of baseline HbA1c for patients on treatment could falsely lower the baseline HbA1c. We anticipate that few patients had previous treatment at the time of enrollment (given relative scarcity of other programs providing NCD care) and that this impact is small. We were not able to capture complications such as hypoglycemic episodes, neuropathy, foot ulceration and retinopathy; while these are assessed for clinically they are not routinely recorded. Finally, the LTFU rate may be lower than reported for two reasons. First, the system lacked standardized documentation of patient

transfers, so patients who transferred care to a facility outside the catchment area may have been classified as LTFU. Second, pharmacy visits for medication refills were not documented in the system. As such, patients who were not seen by a clinic provider in six months but continued to pick up medications were documented as LTFU. Efforts are underway to systematize phone and community health worker-supported contact with patients who miss visits and to facilitate active death notification. Our findings may be hypothesis-generating; further studies are needed to describe longer term outcomes, to identify effective interventions to reduce LTFU, and to explore context specific risk factors of disease.

## Conclusion

In conclusion, our study demonstrates that relatively high retention and low rates of death in patients enrolled in the diabetes program can be achieved, and that for patients who remain enrolled diabetes can be effectively managed with reasonable and sustained glycemic control in a rural resource-limited and multi-center setting. We believe that enabling factors include task-shifting to nurses, embedding services within the rural setting so that they are closer to the homes of patients in need, decentralizing services to more facilities with the support of structured training and strong mentorship, employing point-of-care testing to minimize wait times and frequency of visits, and addressing socioeconomic needs for patients who are particularly vulnerable. However, contributions of these program features, both combined and individually, should be studied more in the future. Further, we found that our diabetes patients in rural Rwanda had low levels of lifestyle risk factors and comorbidities compared with patients in the United States and Europe. These findings may have implications for context-specific prevention and control strategies for diabetes in similar settings and should be further studied with population-level NCD risk factors studies.

## Author Contributions

NT conducted literature review, contributed to conception of manuscript, supported data extraction and cleaning, performed data analysis and interpretation, and led writing and critical review of the manuscript. HH conducted literature review, performed data extraction and cleaning and contributed to writing and critical review of manuscript. SA performed data analysis and interpretation, and contributed to writing and critical review of manuscript. CB and GB contributed to the conception, data interpretation, critical review and revision of the manuscript. BLHG supported data interpretation and performed critical review and editing of manuscript. SD, EH, FM, PFU, CM, GN, DN and ER contributed to organization and critical review of manuscript.

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## Conflicts of Interest

The authors (NT, HH, SA, EH, FM, BLHG, SD, PFU, CM, GN, DN, ER, GB, CB) declared no conflict of interest and none have been paid to write this article by a pharmaceutical company or other agency. This study was not funded by any outside organization. The funders for PIH-supported NCD program had no role in study design, data collection, data analysis, data interpretation or writing of this manuscript. The corresponding author had full access to all the data in this study and had final responsibility for the decision to submit for publication. The authors confirm that this study has not been submitted to any other medical journal, and has not been previously published in any medical journal.

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