

CHAPTER 1

Integration of Chronic Care Services in Rwanda

1.1 The Long Tail of Endemic Non-Communicable Diseases in Rwanda

Non-communicable disease among the poor in Rwanda has a very different face than that seen in middle- or high-income populations. While Rwanda has enjoyed rapid economic growth and political stability in recent years, it remains one of the poorest countries in the world, with a per capita GDP of less than \$1000. Only a quarter of its 10 million inhabitants are 30 or older, and more than 80% live in rural areas. According to the 2005 demographic and health survey (DHS), only 10% of adult women were overweight and more than 20% were severely underweight.^{1,2} Most of the population survives on subsistence agriculture, and food insecurity is a perennial problem. Adjusted data from the 2005 DHS showed that 52% of children under age 5 were chronically malnourished (stunted).³ Within this setting, chronic non-communicable diseases more often result from untreated infections and undernutrition than from the adoption of the unhealthy lifestyles available to poor people in rich countries (see **TABLE 1.1**).

The rural Rwandan health system includes village-based community health workers, nurse-staffed health centers, and district hospitals with generalist physicians. Most districts spend between \$5 and \$15 per capita for health services. On average, patients travel 2 hours to reach the nearest health center. Access to specialists (including internists and pediatricians) is largely limited to facilities in the capital, Kigali, and to the two university hospitals.

In 2005, the government of Rwanda invited Partners In Health (PIH), a Boston-based non-governmental organization, to support the country's initiative to strengthen rural health services. This effort, financed in part by the Clinton Foundation, included building and renovating health infrastructure, supplementing operational budgets, and providing training to local staff. By 2010, the project had reached three rural districts serving more than 750,000 people, and it had increased per capita health spending in those districts to around \$27. During the same period, the government of Rwanda had achieved tremendous improvements in population health. These include extending health insurance to more than 90% of the population, reducing by half the mortality among young children, extending antiretroviral access to more than 80% of

HIV patients in need of treatment (universal access), and increasing the rates of facility-based deliveries.

At the time of PIH's engagement, chronic non-communicable diseases (NCDs) accounted for as much as 30% to 40% of adult hospitalization time in supported facilities. These diseases were over-represented because the patients tended to linger for weeks and months in hospitals—in part because of the lack of reliable outpatient follow-up. These conditions included cardiac, endocrine, renal, respiratory, and hematologic/oncologic disorders.

TABLE 1.1 Burden of Non-Communicable Diseases in Rwanda Linked to Conditions of Poverty

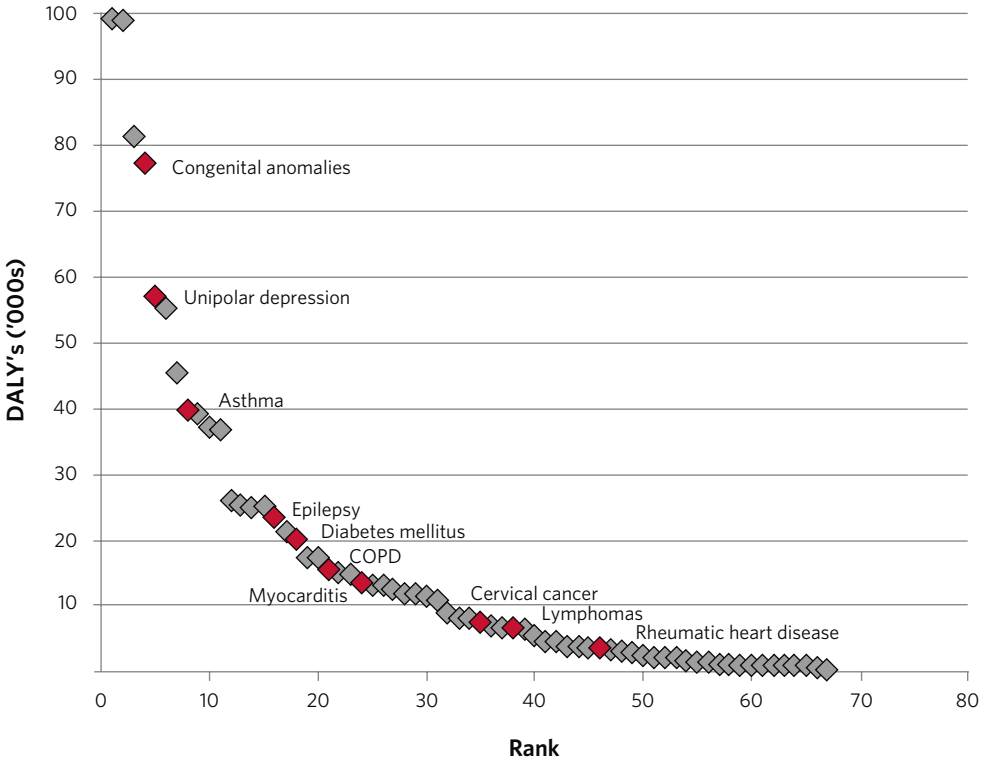
	Condition	Risk factors related to poverty
Hematology and oncology ⁴⁻⁷	Cervical cancer, gastric cancer, lymphomas, Karposi's sarcoma, hepatocellular carcinoma	HPV, <i>H. Pylori</i> , EBV, HIV, Hepatitis B
	Breast cancer, CML	Idiopathic, treatment gap
	Hyperreactive malarial splenomegaly, hemoglobinopathies	Malaria
Psychiatric ⁸	Depression, psychosis, somatoform disorders	War, untreated chronic diseases, undernutrition
	Schizophrenia, bipolar disorder	Idiopathic, treatment gap
Neurological ⁹⁻¹¹	Epilepsy	Meningitis, malaria
	Stroke	Rheumatic mitral stenosis, endocarditis, malaria, HIV
Cardiovascular ¹²⁻¹⁴	Hypertension	Idiopathic, treatment gap
	Pericardial disease	Tuberculosis
	Rheumatic valvular disease	Streptococcal diseases
	Cardiomyopathies	HIV, other viruses, pregnancy
	Congenital heart disease	Maternal rubella, micronutrient deficiency, idiopathic, treatment gap
Respiratory ^{14,15}	Chronic pulmonary disease	Indoor air pollution, tuberculosis, schistosomiasis, treatment gap
Renal ¹⁶	Chronic kidney disease	Streptococcal disease
Endocrine ¹⁷	Diabetes	Undernutrition
	Hyperthyroidism and hypothyroidism	Iodine deficiency
Musculoskeletal ^{18,19}	Chronic osteomyelitis	Bacterial infection, tuberculosis
	Musculoskeletal injury	Trauma
Vision ²⁰	Cataracts	Idiopathic, treatment gap
	Refractory error	Idiopathic, treatment gap
Dental ²¹	Caries	Hygiene, treatment gap

By non-communicable disease, we mean illnesses that may or may not have an infectious origin but persist despite eradication of the infection itself. NCDs pose a special challenge for governments in resource-poor settings. The data on disease burden for young adults and adolescents in sub-Saharan Africa is weak.^{22,23} However, it is likely that conditions that probably account for three-quarters of the disease burden overall are largely infectious (see **TABLE 1.1** and **TABLE 1.2**).²⁴ The remaining quarter of disease burden is distributed in a kind of long tail of NCDs not dominated by any one condition (see **FIGURE 1.1**).

TABLE 1.2 Leading Causes of Death and Disability in Rwanda in Disability-Adjusted Life Years (DALYs)²⁴

Disease	DALYs ('000)	Fraction of total DALYs	
Lower respiratory infections	843	15.6%	74%
Diarrheal diseases	633	11.7%	
HIV/AIDS	557	10.3%	
Maternal conditions	278	5.2%	
Malaria	277	5.1%	
Neonatal infections and other conditions	252	4.7%	
Birth asphyxia and birth trauma	237	4.4%	
Tuberculosis	187	3.5%	
Other infectious diseases (meningitis, STDs excluding HIV, childhood-cluster diseases, upper respiratory infections, Hepatitis B, Hepatitis C)	180	3.3%	
Tropical-cluster diseases	170	3.2%	
Prematurity and low birth weight	155	2.9%	
Protein-energy malnutrition	128	2.4%	
Nutritional deficiencies	102	1.9%	

FIGURE 1.1 The Long Tail of Endemic NCDs in Rwanda



1.2 A Framework for Strategic Planning for Endemic Non-Communicable Disease

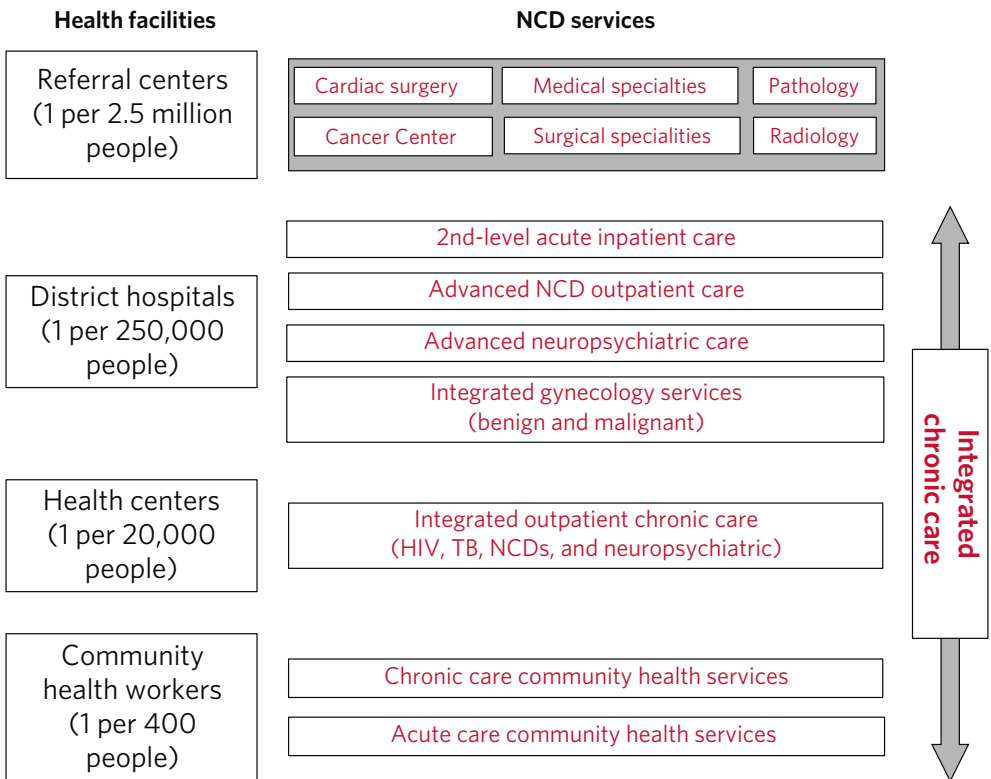
There is increasing evidence that vertical funding for major infectious diseases such as HIV has strengthened health systems around the world.²⁵ However, the problem with vertical planning for endemic NCDs in a country like Rwanda, is that, viewed individually, each non-communicable disease is relatively uncommon. In many ways, the advocacy dilemma associated with endemic NCDs is similar to that faced and addressed by the neglected tropical disease movement, which tackled a multitude of individually low-prevalence parasitic infections through a bundled approach.^{26,27}

The planning issues for endemic NCDs are different from those faced by these infectious diseases, however, because of the heterogeneity of the interventions required to address NCDs. At the same time, entirely disease-specific approaches to individual NCDs threaten to cause more harm than good because they can divert precious manpower and funds from more prevalent health problems.

For this reason, it is crucial to link disease-specific advocacy for these conditions with a parsimonious strategic planning framework. From a policy and planning perspective, it is important to identify the right way to fill the treatment and prevention gaps.

Chronic care integration is one of the units for strategic planning that probably makes sense in some of the poorest health systems. There are many other units that are crucial to care and control of endemic NCDs (see **FIGURE 1.2**). These include referral-level functions such as histopathology and cardiac surgery, as well as district hospital-level service bundles such as integrated gynecologic services (including cervical and breast cancer screening). This handbook focuses on chronic care integration specifically.

FIGURE 1.2 Units of Planning for the Long-Tail Endemic NCDs



1.3 Decentralization and Integration of Chronic Care for Non-Communicable Disease in Rwanda

The process of building chronic care infrastructure has generally involved an incremental decentralization of services, first from the referral center to the district hospital, then from the district hospital to the health center, and finally from the health center to the community health worker. In general, as services are extended away from the referral center, they must become both more simplified and more integrated with other, similar services.

Rwanda began this process in the late 1990s with the decentralization of neuropsychiatric services to district hospitals. By 2005, chronic care for HIV, including antiretroviral therapy, was decentralized to the district level as well. By the end of the decade, chronic HIV care was available at most health centers in the country. Chronic care for NCDs, however, remained an obvious gap in the system. In 2006, the Rwandan Ministry of Health (MOH) began initial efforts to decentralize NCD services from the referral center to the district hospital. This handbook describes the strategy employed.

Other important pilot projects in low-income countries have tackled the problem of providing continuous care for patients with chronic diseases. These approaches have typically not addressed common advanced chronic conditions, such as heart failure, malignancies, and insulin-dependent diabetes.²⁸⁻³⁰ However, scale-up of anti-retroviral therapy for HIV has generated strategies for decentralizing the delivery of complex health interventions for chronic conditions to large populations in resource-poor settings. Rwanda was among the countries that embraced these efforts early and now boasts a robust national HIV diagnosis, treatment, and prevention program.^{31,32}

The Rwandan MOH has worked to adapt this effective model of decentralized HIV care to other complex chronic diseases. The MOH designed approaches to the diagnosis and treatment of endemic non-communicable diseases for use by advanced nurses, clinical officers, or generalist physicians. The protocols use simplified diagnostic techniques based on local epidemiology to place patients into broad categories of disease, corresponding with appropriate clinical pathways. These algorithms do not replace the need for certified specialist evaluation to confirm diagnoses, ensure quality control, and assess the need for surgery. However, the system does allow for more judicious use of scarce specialist time.

At the time of publication, Rwanda had three district level NCD clinics and four health center integrated chronic care clinics, located at PIH-

supported sites. The clinics collectively followed about 2,300 patients with chronic diseases.

This handbook describes protocols for the diagnosis and treatment of chronic cardiovascular, endocrine, and respiratory diseases in the rural Rwandan setting. We hope that it will serve as a resource for both health system planners and clinicians engaged in the delivery of chronic care services. The topics covered mirror those in a forthcoming endemic NCD Training Manual, which addresses in greater detail the pathophysiology of these conditions, as well as pharmacology and examination techniques. Other chronic non-communicable diseases, such as hematologic/oncologic and neuropsychiatric illnesses, will be addressed in future volumes.

1.4 Which Chronic Diseases?

The types of chronic diseases treated and the desirable degree of integration across infectious, non-infectious, and neuropsychiatric conditions depend upon the epidemiology of the local setting as well as the number and prior training of existing health workers. In Rwanda, we have found that HIV, tuberculosis, hypertension, chronic respiratory diseases, diabetes, hyperreactive malarial splenomegaly, malignancies, chronic renal failure, epilepsy, mental health problems, rheumatic heart disease, and heart failure constitute the major chronic diseases presenting at the district-hospital and health-center level. By the late 1990s, Rwanda had already invested in a separate mental health and epilepsy nurse training program and had well-developed HIV and TB programs. In this context, continuity clinics for non-infectious conditions filled a recognized gap in existing chronic care infrastructure. In other settings, it may make sense to have a greater or lesser degree of integration across conditions.

1.5 The District Hospital as a Source of Clinical Leadership

In Rwanda, initial efforts around care of non-communicable diseases were focused at the district-hospital level. This approach provided a mechanism for dissemination. It also ensured that the needs of the sickest patients would be addressed first.³³

In many countries, including Rwanda, the district hospital leaders work closely with the staff of health centers, providing in-service training, clinical mentorship, monitoring, and evaluation. Additionally, provision of high-quality services at district hospitals can help reduce transfers to referral centers. Investment in the development of clinical program leaders at the district level of the health system can move the manage-

ment of more advanced conditions away from tertiary facilities, while at the same time creating a pathway for further decentralization of uncomplicated chronic care to sites located closer to the homes of patients. During this period of district strengthening, patients may well require direct subsidies to pay for transportation.

In some contexts, physicians might staff district-level continuity clinics entirely on their own. In Rwanda, nurses run the clinics because of a shortage of doctors. The scarce physician pool is, however, large enough to provide oversight. The physician role includes confirmation of new diagnoses and consultation on the management of complex cases. This approach mirrors Rwanda's chronic care infrastructure for HIV.³¹

Each PIH-supported district hospital in Rwanda has an advanced chronic care clinic for non-infectious diseases. These clinics see patients four to five days a week. They are staffed by two to three nurses who see 10 to 20 patients per day. Physicians supervise initial consultations, consult on complex cases, and meet regularly with the nurse program leader to discuss work plans, budgets, and program evaluation. Specialists from referral centers visit the clinic every one to two months to confirm diagnoses and provide ongoing training.

At first, when the number of patients was small, people with different conditions were seen on the same day. However, once patient volume increased, we found it useful to designate specific days of the week for particular diseases. This approach streamlined patient care and education and allowed for more focused interactions between nurses, district hospital physicians, and visiting specialists from referral centers. This approach also created a platform for more organized clinician training on specific diseases.

Initially, we trained advanced nurses at district clinics through daily, direct patient management with physicians. As the program grew, we formalized this process into a three-month-long training curriculum in advanced chronic disease management and basic echocardiography. The program includes both didactic and practical training by physicians and previously trained advanced nurses.

At the same time, an effort to develop a training strategy for health center-level clinicians required greater coordination of chronic care services. In this model, program leaders in NCDs, neuropsychiatry, and infectious diseases (HIV and TB) form a chronic care team that trains and mentors a group of health-center clinicians in the basic management of these conditions (see **FIGURE 1.3**). **TABLE 1.3** provides a sample schedule of the clinical and training duties of district-level clinicians.

FIGURE 1.3 Integration of Human Resources for Chronic Care

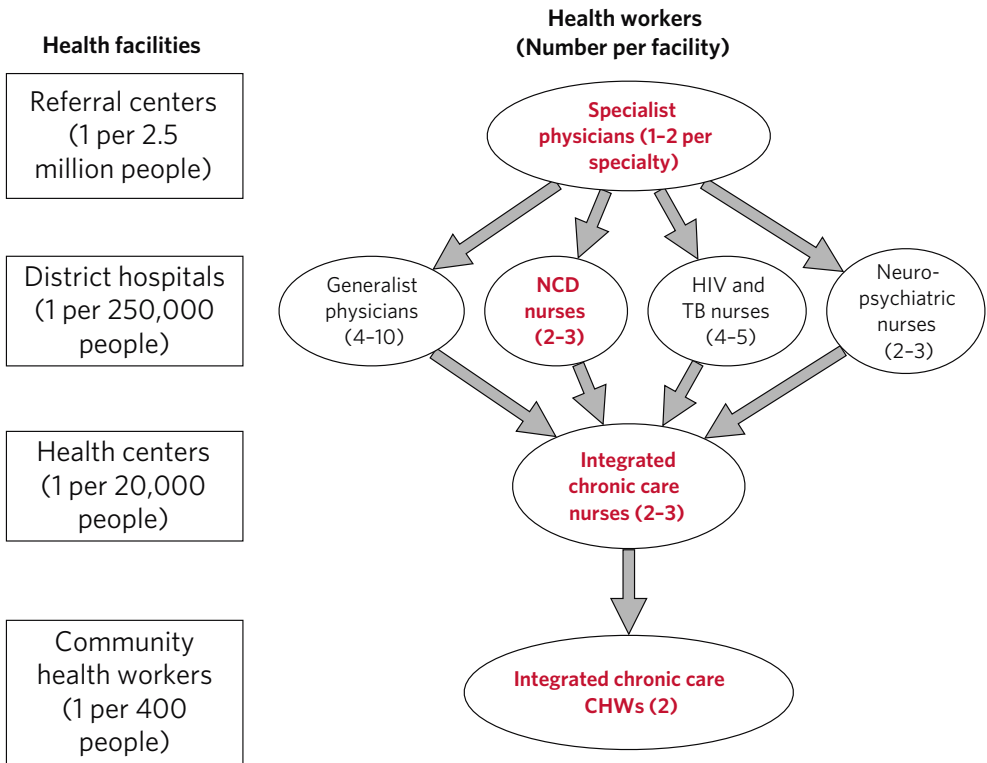


TABLE 1.3 Sample District Hospital-Based Clinician Schedule

	Monday	Tuesday	Wednesday	Thursday	Friday
Nurse 1	Preceptorship of health center nurses	Teaching (didactics)	District hospital heart failure clinic and preceptorship	Teaching (didactics)	Administration
Nurse 2	District hospital hematology/oncology and preceptorship	District hospital chronic respiratory disease and preceptorship	Teaching (didactics)	District hospital advanced diabetes and hypertension clinic and preceptorship	Teaching (didactics)

1.6 District Inpatient Care

A functional system of outpatient management of chronic disease relies in part on adequate inpatient services. District hospital physicians and nurses require education on inpatient management of non-communicable diseases, such as treatment of decompensated heart failure and diabetic ketoacidosis. For generalist physicians working at district level, this training can take place either in medical school or as a part of a post-graduate program. This guide does not address inpatient management specifically, but we have contributed to the World Health Organization's (WHO) forthcoming Integrated Management of Adult and Adolescent Illness District Clinician Manual for hospital care, and we refer interested readers to that guide.

High-quality inpatient care also requires good communication between outpatient and inpatient clinicians. At PIH-supported district hospitals in Rwanda, we have adopted several strategies to encourage this practice, particularly at the time of patient admission and discharge. When a patient is admitted to the district hospital, the outpatient clinician completes a transfer note and verbally discusses the case with the receiving physician. Depending on the complexity of the case, the inpatient physician is encouraged to discuss the case with other district and specialist physicians who have helped manage the patient in the ambulatory setting. At discharge, the inpatient physician completes a discharge form with pertinent information such as discharge medications and lab values, and the form is placed in the patient's chart and returned to the clinic. The patient receives education, assignment of a community health worker if indicated, and an outpatient clinic appointment prior to discharge.

1.7 Health Centers: Case Finding, Initial Management, and Chronic Care

As the chronic NCD program develops, district-based clinical leaders should begin to train clinicians at the health-center level to provide basic services for common non-communicable diseases. Given the smaller number of clinicians working at health-center level and the smaller volume of patients, chronic care services may require a higher level of integration with other services, such as HIV treatment and neuropsychiatric care. Depending upon the number of staff available, health centers may want to train health care workers in basic management in broad clinical areas, such as chronic care, acute care, and women's health. This would constitute an in-country adaptation of WHO integrated management protocols such as Integrated Management of Childhood Illnesses, Integrated Management of Adult and Adolescent Illness, and Integrated

Management of Pregnancy and Childbirth. District-based clinical leaders are well poised to facilitate these trainings, which should include a mix of didactics and supervised clinical work with ongoing, on-site mentorship, monitoring, and evaluation. This process requires district-hospital staffing to include built-in time for clinician leader travel and training activities. Decentralization of clinical services also requires establishment of drug supply chains that include the health-center facilities. Because expansion of services to the health-center level has significant budgetary implications, decentralizing services may require strategies for additional financing developed by the MOH in partnership with other stakeholders.

1.8 Referral Centers

Historically, concerns about consumption of public health care budgets for services at the referral-center level have dominated much of the discourse around non-communicable disease prevention and treatment in resource-poor settings.³⁴ However, in the treatment of chronic conditions, only tertiary centers can provide certain diagnostic and therapeutic interventions efficiently and safely. As district hospitals improve delivery of acute and chronic care for patients with non-communicable diseases, referral centers can focus on those activities best provided at the tertiary level. These include specialty consultation for complex endocrine cases; echocardiography and cardiac surgery for rheumatic and congenital heart disease; pathologic diagnosis, surgery, chemotherapy, and radiation for malignancies; and computerized tomography and bronchoscopy for chronic respiratory disease. We have tried to finance outreach by specialists from referral centers to district hospitals in such a way as to promote public and governmental support for strengthening the national health system.

This guide does not cover the important and complex process of establishing essential specialty services such as cardiac surgery and oncologic care at referral centers. An individual country's human resources, health budgets, and epidemiology should guide decisions about how to prioritize investments in national referral services. We believe there is an ethical obligation to care for salvageable patients with advanced conditions, and we suspect that such services can often provide good value for money. At the same time, achieving good outcomes from advanced interventions often requires a system that provides decentralized follow-up and continuing care. This guide addresses these issues with regard to post-cardiac surgery follow-up in chronic care clinics.

1.9 Out-of-Country Referral

Among our chronic care patients, a subset require services not available nationally, such as cardiac surgery or radiation oncology. In Rwanda, the MOH has developed relationships with several regional cardiac surgery centers. PIH in Haiti has built similar relationships with a regional cardiac center. Increasingly, regional centers in low- and middle-income countries have begun to provide these services far more efficiently than facilities in the United States or Europe.

1.10 Screening

In some settings, community-based screening for common chronic diseases may be a reasonable approach to increase case finding. At the very least, community health workers engaged in acute care should be trained in recognizing the symptoms and signs of decompensated chronic diseases. Screening only makes sense, however, in a setting with established and effective chronic care services.

1.11 Principles of Patient Follow-Up and Retention: Community Health Workers and the Electronic Medical Record

Chronic care services in any setting struggle to achieve good patient follow-up and retention. While directly observed therapy for HIV treatment remains controversial, PIH-supported HIV programs have achieved exceptional patient retention and clinical outcomes.³⁵ In this system, community health workers, or *accompagnateurs*, visit patients on a daily basis to provide psychosocial support, administer medications, ensure adherence, and facilitate medication refills and clinic appointments. We have adopted a similar model for patients with other advanced chronic conditions, such as heart failure, insulin-dependent diabetes, and malignancies. The health workers also serve as a link between the health facility, finding patients who are lost to follow-up, and in some instances referring new or decompensated cases. Community health workers are becoming increasingly involved in wider case-finding activities, in patient education, and in the provision of acute, chronic, and palliative care for a range of conditions.

Good patient follow-up also relies on an organized system of record-keeping. Rwanda has adopted an electronic medical record system to store patient information, track visits, and monitor clinical progress. Clinicians record visits on standardized intake and follow-up forms that collect key patient demographic and clinical characteristics. Data officers in turn enter information into an electronic medical record that facilitates both patient follow-up and program evaluation and monitoring.

We have developed modules for the OpenMRS electronic medical record system, an open-source platform initiated collaboratively by PIH and the Regenstrief Institute. These modules are made publicly accessible at <http://modules.openmrs.org/modules>.

1.12 Equipment, Medication Procurement, and Costs

The WHO Essential Drug list includes most of the medications used in our programs. However, regional, district, and health center formularies may not include all of these drugs. Even when medications are on local formularies, the supply chain systems in place for antiretroviral (ARV) therapy or antituberculous medications have not yet extended to other chronically administered medications. Increasing access to these medications requires clinician training on their use as well as supplemental funding. Chronic disease already poses a large burden on patients in the form of lost income and the expense of clinic visits. In this context, patients cannot reasonably take on the full cost of medications that they must take over long periods of time. Chronic care programs should adopt the approach of ARV programs; they should provide chronically administered medications free or at minimal charge to patients at the point of care. **APPENDIX B** provides specific information on our modeled program costs for each condition.

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