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PROCEEDINGS

CHRONIC CARE DESIGN MEETING

Transforming Health
Systems and Improving
Quality Care for Chronic
Conditions in Africa

May 26-31, 2010 | Kampala, Uganda

MARCH 2011

This report was prepared by University Research Co., LLC (URC) for review by the United States Agency for International Development (USAID). It was authored by Whitney Isenhower and Robert Kyeyagaire of URC. It was carried out by the USAID Health Care Improvement (HCI) Project made possible by the generous support of the American people through USAID.

Front cover:

Entebbe Hospital outside of Kampala, Uganda. Meeting participants visited hospitals and health centers on May 27, 2010 to understand how patients receive care for chronic conditions, such as HIV. *Photo by Marianne Drowne, URC.*

Meeting participants pose with staff at the Entebbe Hospital. *Photo by Marianne Drowne.*

USAID's Jim Heiby speaks to Chronic Care Design Meeting participants. *Photo by Marianne Drowne.*

HCI's director, M. Rashad Massoud, and meeting participants map the typical "patient's journey" for receiving care at the Luwero Health Center. The map shows the steps patients take to obtain care during their visit to the health center. *Photo by Marianne Drowne.*

PROCEEDINGS

**Chronic Care Design Meeting:
Transforming Health Systems
and Improving Quality Care for
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MARCH 2011

Whitney Isenhower

Robert Kyeyagalire

DISCLAIMER

The views expressed in this publication do not necessarily reflect the views of the United States Agency for International Development or the United States Government.

Acknowledgements: This report summarizes the key discussions and conclusions of the May 26–28, 2010, Chronic Care Design Meeting held in Kampala, Uganda, which brought together experts in chronic care and HIV with leaders of Uganda’s health system. The meeting was convened by the United States Agency for International Development (USAID) Health Care Improvement (HCI) Project and the Ministry of Health (MOH) of Uganda to explore how to apply key principles of care for chronic conditions to the management of HIV in Uganda.

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Special thanks to Dr. Kathy Reims and Ms. Connie Davis for developing the Catalog of Changes (Appendix E) for discussion at the meeting.

The report summarizes the meeting’s proceedings. Ms. Whitney Isenhower prepared the report with inputs from Mr. Robert Kyeyagalire. Dr. M. Rashad Massoud, Dr. Nigel Livesley, Dr. Kathy Reims, Ms. Connie Davis, and Ms. Lani Marquez reviewed the report and provided valuable feedback.

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Acronyms

AIDS	Acquired immune deficiency syndrome
ART	Antiretroviral therapy
ARV	Antiretroviral (medication)
CHW	Community health worker
HCI	USAID Health Care Improvement Project
HIV	Human immunodeficiency virus
IGA	Income-generating activity
JCRC	Joint Clinical Research Centre
MOH	Ministry of Health
NGO	Non-governmental organization
PACE	Program for Accessible Health, Communication and Education
PEPFAR	U.S. President's Emergency Plan for AIDS Relief
PLWHA	People living with HIV and AIDS
PMTCT	Prevention of mother-to-child transmission
QI	Quality improvement
TASO	The AIDS Support Organisation
TB	Tuberculosis
URC	University Research Co., LLC
USAID	U.S. Agency for International Development
VHT	Village health team

Executive Summary

As patients throughout Africa are living longer with chronic conditions—those with which patients live for many months or years, such as HIV, hypertension, and diabetes—health systems must adapt to meet their needs. This report details the discussions and conclusions of a Chronic Care Design Meeting held in Uganda to explore how to improve care for these conditions, particularly HIV and especially in Africa. Officials from Uganda’s Ministry of Health (MOH), the United States Agency for International Development (USAID), the USAID Health Care Improvement (HCI) Project, and experts in HIV and chronic care, participated. The meeting was held at Speke Resort in Munyonyo, part of Kampala, Uganda, from May 26–28, 2010.

Uganda has been a leader in HIV care in African nations—exhibited by the country’s implementation of programs such as the MOH Quality of Care Initiative in HIV and AIDS. Its health system is exemplary for analyzing a country’s current and future ability to respond to chronic care conditions.

During the meeting, about 50 participants engaged in group work, discussions, and presentations in order to understand the current Ugandan chronic care system and how it can be improved and adapted to provide better care for patients with long-term illnesses and medical conditions.

On day two, participants broke into three groups to visit a hospital in Entebbe and health centers in Luwero and Kangulamira, gaining a firsthand understanding of how chronic care conditions currently are being handled in facilities and the systems that surround that care. After viewing some of the successes (utilizing expert clients, village health teams, and patient follow-up), participants gained knowledge of what currently works in the Ugandan care system and how this can be adapted to suit chronic care needs.

Next, starting with the World Health Organization (WHO)’s Care for Chronic Conditions model, participants concluded that the three-tiered model focusing on patients and family, community partners, and health care teams should be restructured to support a **patient-centered approach** in chronic care. Key recommendations include:

- Adopt broad, high-level commitment to strengthening care for patients with chronic conditions.
- Test the developed application of the principles of chronic conditions care in Uganda to build a strong evidence base on how to best deliver good care.
- Strengthen existing systems and structures, such as village health teams (VHTs), community-based organizations, and expert patients.
- Educate, coach, and support patients, providers, and communities on delivering good care for people living with chronic conditions.
- Implement an effective health information system to support the management of chronic conditions.
- Recognize the importance of working in teams across existing sites.

Conclusions from the workshop and success stories from Uganda were presented on May 31, 2010, the first day of a four-day international conference on “Transforming Health Systems and Improving Quality Care for Chronic Conditions in Africa,” held in Kampala. More than 250 participants from 10 African countries (Cote d’Ivoire, Nigeria, Ethiopia, Rwanda, Kenya, Tanzania, Namibia, Malawi, South Africa, and Uganda) came to the Imperial Royale Hotel and listened to highlights from the Chronic Care Design Meeting and learned how to redesign a health system to meet chronic care conditions in their home countries.

As a result of the meeting, the Uganda’s MOH resolved to adopt a high-level and comprehensive commitment to improving its health care system so that it can more effectively serve people with chronic conditions and acute illnesses. It was agreed that the MOH will facilitate the development and testing of the principles of chronic conditions care, using HIV as an example, in order to determine how to provide excellent care for patients with chronic conditions. This will occur through a national

demonstration project, carried out in one district in Uganda, and will be complemented by ongoing MOH involvement and advocacy. HCI, along with partners HIVQUAL International and the Institute for Healthcare Improvement (IHI), will join forces with University Research Co., LLC (URC)'s Strengthening Uganda's Systems to Treat AIDS Nationally (SUSTAIN) project in order to meet common project objectives and reach health facilities at different levels in Uganda.

This report includes extensive tables in the annexes listing ways that participants at the design meeting recommend improving health care services for patients with chronic conditions in Africa.

I. Introduction

Many health systems worldwide are set up to diagnose and treat acute illnesses, such as malaria and other infections, yet patients with chronic conditions, including HIV, cancer, and diabetes, have different needs. While diagnosis remains important, chronic care patients have a greater need than acute care patients to be involved in their own care and receive long-term support even when they feel well. Health systems designed to manage acute illnesses lack well-developed structures to 1) help patients learn to manage their condition and 2) provide ongoing routine care. Health systems will struggle to cope with the global burden of chronic conditions as it increases. This concern is especially pertinent in African countries, where health systems often lack resources, funds, and infrastructure. While it is positive that patients now are living longer with chronic illnesses, their doing so also challenges Africa's already-struggling systems.

The USAID Health Care Improvement (HCI) Project convened the meeting in Uganda because it is and has long been a leader among African nations in its quick and efficient response to curtailing the HIV epidemic and providing care and treatment for patients. The meeting aimed to address chronic care for people living with HIV and other chronic conditions in Uganda and Africa. Some 50 participants—Ministry of Health (MOH) officials; University Research Co., LLC (URC) staff and consultants working on HCI; USAID, donor, and implementing partner representatives; and chronic care experts—convened May 26–28, 2010 at the Speke Resort in Munyonyo, part of Kampala, Uganda to discuss current chronic conditions care in Uganda and how it can be improved, adapted, and better meet patients' needs.

The meeting's results were then presented at the opening day of a four-day conference in Kampala that convened Uganda partners and representatives from nine other African nations: Cote d'Ivoire, Nigeria, Rwanda, Kenya, Tanzania, Ethiopia, Malawi, South Africa, and Namibia.

The design meeting's objectives were to:

- Design a chronic care model for Uganda based on the World Health Organization (WHO) model.
- Discuss and pinpoint successful approaches to implementing chronic care in Uganda.
- Present the results at the subsequent conference in Kampala.

This report summarizes the discussions and conclusions of both the design meeting and the follow-on conference session. It can serve as a guide for nations, especially in Africa, to implement their own chronic care approaches, particularly in regard to the HIV epidemic.

II. Care for Chronic Conditions

In response to the fact that people with chronic conditions have different health needs than those with acute conditions and that chronic conditions often extend throughout a lifetime, experts in chronic illness have developed a vastly different approach to care. The approach is expressed by the Chronic Care Model, which seeks to foster productive interaction between activated patients and proactive care teams to ensure people living with chronic conditions reap the best benefit from the health system and have good functional and clinical outcomes.

This model helps programs control costs by enabling appropriate use of self-care and low-cost services based in the family and community. The model was developed in the United States, spurred by evaluations of successful diabetes care systems. Further work across a variety of chronic conditions found that six components of care were associated with successful chronic conditions care programs: 1) self-management support for patients, 2) changes in delivery system design to foster more time to focus on the special requirements of people with chronic conditions, 3) decision

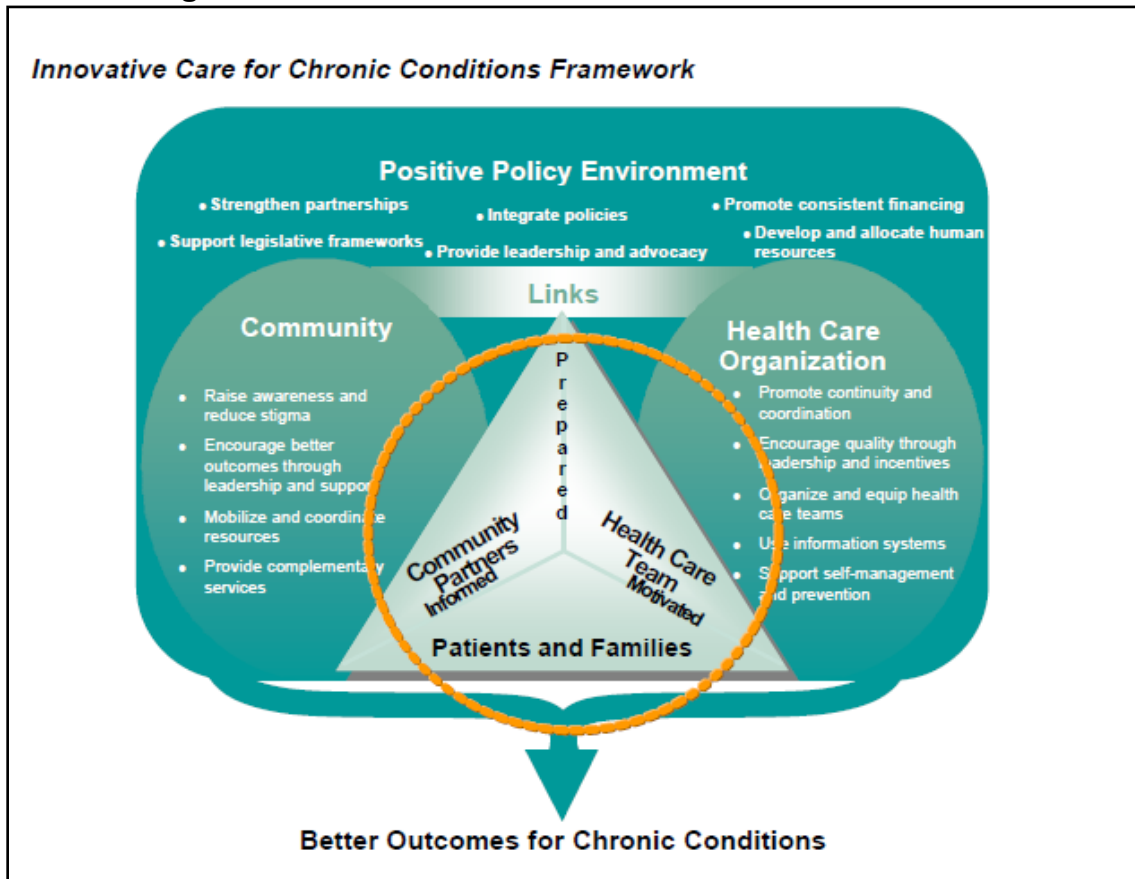


support to help ensure that evidence-based practices are provided, 4) clinical information systems to improve patient records and allow aggregated data to be reviewed, 5) community links so that patients have support close to home, and 6) organizational commitment to providing good chronic care.

WHO endorsed this chronic care strategy in a seminal report entitled, *Innovative Care for Chronic Conditions: Building Blocks for Action* (WHO, 2002). It presents a “road map” for countries and health systems to update their health care to meet the needs of people with chronic conditions. The proposed building blocks of the Innovative Care for Chronic Conditions Framework are relevant for both prevention and disease management in health care settings. Recommendations are given for improving the quality of patient interactions, organization of health care, community involvement, policy, and financing systems.

Figure 1 depicts the Innovative Care for Chronic Conditions Framework, which WHO endorses, that emphasizes patient and family, community, the health care facility, and the health system all contribute to a patient’s health and well-being. It renders the core triad of patients and families, community partners, and health care teams as the cornerstone of chronic care.

Figure 1: Innovative Care for Chronic Conditions Framework



III. Background on Chronic Care for Patients with HIV in Uganda

Uganda has a population of 31.9 million people, with 1.3 million residing in Kampala, the capital. One of the country’s most pressing chronic conditions is HIV. Uganda has an HIV prevalence of 6.4%, with women exhibiting a higher HIV infection rate than men. The highest infection rate exists in the 15–49 age group. There is also a large gender gap in accessing care: 65% of HIV-positive females access HIV care while only 34% of HIV-positive males do.

Uganda had an established National Committee for the Prevention of AIDS, which evolved into the AIDS Control Program in 1986. When the MOH initiated its plan for rapid scale-up of antiretroviral therapy (ART) in 2005, issues emerged regarding the quality of care. To ensure adequate, extensive care, the MOH introduced a national strategy, the Quality of Care Initiative, to improve access to and the quality of HIV services countrywide.

Currently, more than 400,000 Ugandans receive HIV care and 373,836 are in need of ART. The MOH has established several components of comprehensive HIV care: counseling and testing for HIV infection, prevention of mother-to-child transmission (PMTCT), and clinical management of HIV. Uganda has several service-delivery levels offering these components:

1. National referral hospitals
2. Regional referral hospitals
3. District and missionary hospitals
4. Health center IVs and a few health center IIIs

Uganda has systems by which chronic care can be scaled up, including the WHO Integrated Management of Adolescent and Adult Illness (IMAI) model, which addresses “acute care, chronic HIV care with ART, general principles of good chronic care, and palliative care” (WHO, 2004). This approach is applied to chronic care, and materials related to this model have been developed in Uganda.

IV. Meeting Agenda

The meeting brought together MOH officials, HCI headquarters and Uganda personnel, international consultants, and partner Ugandan organizations and HIV care providers to address, discuss, and formulate effective chronic care approaches in Uganda and across Africa. **Appendix A** lists the attendees and implementers.

The three-day design meeting aimed to introduce participants to chronic care concepts and emphasize the importance of ensuring the chronic care redesign would be specific to Uganda’s system and not imported from elsewhere. While examples for implementing chronic care from other countries were shared, they served as models to be adapted for Uganda.

On Day 1, meeting participants were split into groups centered on the WHO Model’s core triad (patients and families, community, and health care organization) to analyze how each can best contribute to better chronic care. On Day 2, participants visited three health facilities (in Entebbe, Luwero, and Kangulamira) to explore how two health centers and a hospital currently handle chronic care and how improvements in this care can be implemented in Uganda. Day 3 consisted of further group work toward designing a better chronic care model and system for Uganda.

On May 31, MOH officials and HCI staff presented findings from the meeting at a larger conference on transforming health systems to provide chronic care. More than 250 participants from 10 African countries discussed how to make chronic care for patients with HIV and other chronic conditions more patient centered.

The proceedings of both the design meeting and conference presentation follow.

Day 1: Wednesday, May 26, 2010: The design meeting began with presentations on chronic care concerns in Africa and how Uganda is addressing them. That afternoon, participants were split into three groups by the core triad to analyze how each part does and can contribute to chronic care systems. Each group presented in a plenary session to offer a comprehensive understanding of what is happening with chronic care in Uganda. Specifics of the groups’ findings are discussed in this document’s annexes.

Dr. Nigel Livesley presented how management of acute illnesses differs from that of chronic conditions: the former is reactive and the latter is proactive. Dr. Kathy Reims and Ms. Connie Davis presented on how chronic care is most effective when all parts of a system (patients, families, communities, and health care facilities) come together to best decide how to provide this care.

Chronic care also challenges human resources, and part of the concern is how this issue demands changes in the ways health workers work and how to articulate this idea in revising the national plan. Also needed are education and information for the public and ways to communicate them in implementing effective chronic care systems.

Dr. Elizabeth Namagala, who is with the MOH Uganda, presented on the country's current HIV and chronic care situation. Key points from her presentation include:

- Uganda's HIV prevalence is 6.4% of the population.
- In 2001, documentation detailing guidelines on HIV care and treatment was released and later published as the National Antiretroviral Treatment and Care Guidelines for Adults and Children.
- In 2004, there was a rapid, nationwide expansion of ART.
- There are about 1 million people currently living with HIV in Uganda.
- Available data for those living with HIV are available only on people who are documented by registers in health facilities.

Uganda has three models of ART care:

- **Facility-based care**, which is usually managed by nurses who need to be trained since they have inadequate training in HIV care.
- **Community-based HIV care**, which is like The AIDS Support Organisation (TASO) Uganda model, which emphasizes the home-based care approach that is cheaper than the facility-based model and requires less infrastructure.
- **Outreach-based care (care provided to patients in their own setting, at home, etc.)**, which can improve access to HIV care, especially in hard-to-reach areas, but it might be hard to document and monitor if not well integrated into the host facility.

After a plenary group discussion of the existing challenges for implementing chronic care in Uganda, participants broke into three groups, as noted above, to answer the following questions:

1. What is working in terms of chronic care?
2. What are the related opportunities?
3. What are the policy questions?

Individual group work was then presented to the plenary group for participants to gain an understanding of how chronic care is currently implemented and what opportunities for improvement exist among the triad elements. As the first day highlighted participants' initial impressions and thoughts about the Chronic Care Model and what would come out of the meeting, several key points were made about what could be included in the final model for Uganda:

- It is important for the chronic care model to also take acute conditions into account since both exist simultaneously.
- Prevention of new opportunistic infections should be included since such infections would affect the effectiveness of care.
- Chronic care should be implemented with efforts to ensure active community involvement.
- Leveraging existing structures and organizations (such as VHTs, community-based organizations, etc.) often can be more effective, both in organizational and monetary terms, for implementing chronic care initiatives.

Day 2: Thursday, May 27, 2010: Three 15-member groups of HCI staff, Uganda MOH staff, and consultants each visited one hospital and two health care centers in three Ugandan towns: Entebbe, Luwero, and Kangulamira. These visits enabled participants to observe how care is being delivered today, to map the patient's journey in each facility, and to discover the barriers that impede patients from receiving adequate care and remaining healthy. **Appendix B** provides the guide given to meeting participants for the patient journey mapping exercise.

The facility visits and subsequent discussions among meeting participants highlighted several issues that currently inhibit providing good chronic care in Ugandan health facilities:

- Finances may prevent some patients from getting a CD4 test, which is expensive to conduct.
- The MOH and health center have different systems for keeping medical records, which can lead to inconsistent data.
- Centers often see hundreds of patients a day with minimal clinic staff (three clinicians in the Luwero health center see 250 patients per day). Thus, patients do not receive proper care and are rushed in and out of appointments.
- Antiretrovirals (ARVs) are not always well stocked due to inadequate supplies from the National Medical Stores and inaccurate requisitions, as well as corruption, lack of funds, and other factors at the national level.
- A clinic does not necessarily offer the services that patients need, and a patient may not be able to access a larger health care center that does, so he or she may receive inadequate care or not visit a health center at all, receiving no care. Also, patients who live farthest away from health centers tend to be sicker, partly due to inconsistencies in their ability to access health care.
- Patients often are not tracked appropriately or at all.
- Many clinics do not have X-rays and microscopes.
- Limited electricity and constant power shortages can damage equipment and lead to its limited use, inhibiting its being used to provide good care.
- Many staff members are not trained to give proper ART.

Appendix C summarizes the key challenges identified by the groups and proposed solutions based on experiences in Uganda and other countries.

Day 3: Friday, May 28, 2010: On the final day of the design meeting, participants met in the same three site-visit groups, but the groups were renamed by the core triad element. Each group discussed the role of each element in a well-functioning chronic care system. Patients can manage their own care and seek adequate resources and treatment for living healthy and positively. Family members can support the patient by maintaining an honest and open relationship that ensures the patient stays physically and mentally well. Community members and groups help support patients and their self-management by linking them with health facilities, care centers, and support groups. Community members can become informed about chronic conditions, how they can be addressed, and how care can be obtained in case they or anyone they know is diagnosed with a chronic condition. Finally, the system/policy level can provide the basis for implementing ingrained, effective, and long-lasting chronic care systems.

After discussion and group work, group members presented findings and suggestions for improving chronic care to the plenary group (see the Recommendations section of this report).

Day 4: Monday, May 31, 2010: At the start of a four-day conference that showcased sessions from the 2010 International Forum on Quality and Safety in Healthcare and instructed on how to use a gaps analysis framework to improve ART care for patients living with HIV, highlights from the Uganda Chronic Care design meeting were presented to more than 250 participants from 10 African nations: Cote d'Ivoire, Nigeria, Ethiopia, Rwanda, Kenya, Tanzania, Namibia, Malawi, South Africa and Uganda. Conference participants heard an MOH presentation of existing chronic care in Uganda and its successes, including the Quality of Care Initiative. HCI consultants Connie Davis and Kathy Reims presented the essentials of all levels and people coming together to provide proper chronic care, which is holistic in its approach.

In the afternoon, participants split into groups and discussed chronic care centered on three themes: 1) changes for patients and families; 2) the health care team; and 3) community support. Participants also attended sessions about policy changes for the Uganda system and implications for chronic care design in other countries. The policy session focused on the importance of maintaining proper funding for

chronic care issues, task shifting to address human resource shortages, ensuring systems are adequately equipped to address chronic care (medications stocked, well staffed, trained clinicians, etc.), and the importance of incorporating monitoring and evaluation and quality improvement interventions into chronic care. Conclusions from the groups' discussions are included in **Appendix D**.

Chronic care success stories from other countries were discussed in the policy implications session, with a key success story being chronic care clubs used in South Africa. More than 750 patients are on treatment in groups of 30 at a clinic using these clubs. The groups consist of patients living with HIV who advise one another during the course of the illness and provide psychological support. Group members keep clinic appointments and are given follow-up appointments a month or two in advance. If a member misses a scheduled appointment, there is a set make-up appointment time. The clubs are voluntary, and members must be stable on ART for six months before they can join one.

Through the introduction provided to the chronic care model and learning how policies and health systems in various countries have been adapted to a chronic care model, conference participants saw a patient-centered approach as the basis for implementing a successful chronic care intervention.

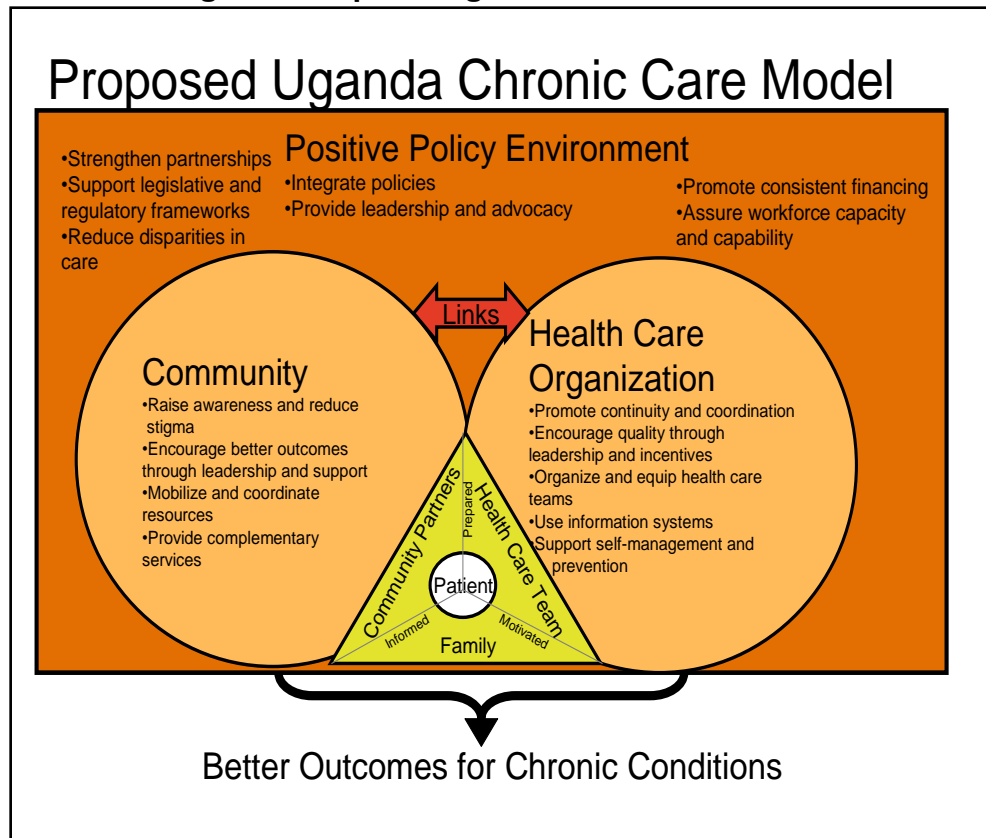
V. Recommendations from the Chronic Care Design Meeting

At all levels of care, long-term changes are necessary to incorporate proposed strategies and changes into the acute health care system to ensure it also provides excellent chronic care. Keeping in mind the system merely needs to be improved and not necessarily rebuilt from scratch, it is important to continue implementing the parts of the system that currently work well.

Participants agreed chronic care should focus on the patient as he or she is the one in charge of his or her own care and is the individual most affected by any chronic care system. A small group met to redesign the model adapted to the Ugandan context, pictured in Figure 2.

The proposed Uganda Chronic Care Model puts the patient at the center of care, surrounded by a trio of beneficial relationships with community partners, the health care team, and the individual's family. In turn, the larger community and health care organization existing in a positive policy environment support this central group of relationships.

Figure 2: Proposed Uganda Chronic Care Model



Participants concluded good chronic conditions care can improve the health of Ugandans by:

- Preventing complications of chronic conditions, which is achieved by early disease detection and treatment that results in keeping people healthier longer
- Improving the quality of care provided for chronic conditions and disease prevention
- Reducing the cost of care and the burden of suffering in communities over time by decreasing the impact of end stage diseases, keeping the workforce healthy, delivering care at the local level, and availing the help of individuals, families, and communities

Table 1: Change Concepts to Improve Care for Chronic Conditions

Patient

- Take care of the illness using core self-management skills.
- Maintain important daily activities.
- Manage emotional changes.
- Engage in health promotion and prevention activities.

Family

- Support the patient to take care of the illness.
- Help the patient maintain important daily activities.
- Support the patient who experiences emotional changes.
- Engage in health promotion and prevention activities with the patient.

Health Care Team

- Design care delivery to meet patients' needs.
- Support decisions with evidence.
- Use clinical information systems at the point of care.
- Support self-management for chronic conditions, prevention, and risk reduction.

Community Partners

- Develop relationships with local care team.
- Support patients to live successfully in the community.
- Harmonize with local, district, regional, and national plans.
- Design and use feedback mechanisms to improve programs.

Health Care Organization

- Promote continuity and care coordination over time between sites and across health system levels (community, clinic, district hospital, regional hospital, etc.).
- Encourage quality through leadership and incentives.
- Organize and equip health care teams.
- Use information systems.
- Support self-management and prevention.

Community

- Raise awareness and reduce stigma.
- Encourage better outcomes through leadership and support.
- Mobilize and coordinate resources.
- Provide complementary services.

Positive Policy Environment

- Strengthen partnerships.
- Support legislative frameworks.
- Integrate policies.
- Provide leadership and advocacy.
- Promote consistent financing.
- Ensure workforce capacity and capability for provision of chronic care.
- Reduce disparities in care (equity and equality).

VI. Next Steps for Chronic Care Implementation in Uganda

To demonstrate how integrating chronic care into health systems is strategically beneficial, evidence must be produced that demonstrates improved outcomes, cost-effectiveness, and a more efficient workload for the health workforce. HCI is committed to building this evidence as part of its improvement work across workforce, clinical services, and health systems-strengthening activities. A key element for successfully strengthening health systems to deliver cost-effective chronic care services will be local engagement and ownership across all levels of the health system, from patients, to providers, to senior managers, to MOH officials. HCI will actively promote such engagement in line with the overall direction of the President's Global Health Initiative.

HCI is currently supporting the Uganda MOH to implement two major activities that focus on improving chronic care: 1) integration of chronic care best practices into HCI-supported HIV improvement work and 2) a demonstration to improve palliative care (pain management) in two districts.

Chronic Care Initiative: As a result of the Chronic Care Design Meeting, the Uganda MOH resolved to adopt a broad, high-level, and comprehensive commitment to improving its health care system so that it can more effectively serve people with chronic conditions and acute illnesses. It was agreed the MOH will facilitate the development and testing of the principles of chronic conditions care, using HIV as an example, in order to determine how to provide excellent care for affected patients. This will occur through a demonstration project in a Ugandan district and will be complemented by ongoing MOH involvement and advocacy.

Necessary Steps to Improve Care for Patients with Chronic Conditions in Uganda

- 1. Demonstrate commitment** by adopting a broad, high-level, and comprehensive commitment to the health care system so it can effectively serve people with chronic conditions and acute illnesses. This requires prioritizing resources and personnel. The commitment to improving care for chronic conditions should be clearly communicated within the MOH, nongovernmental organizations (NGOs), health care providers, and the public.
- 2. Test and develop the application** of the principles of chronic conditions care using HIV as an example to demonstrate how to provide excellent, cost-effective care for patients with chronic conditions. These national demonstration projects will develop procedures and staffing that can be readily reproduced in other centers and for other chronic conditions.
- 3. Strengthen existing systems:** Uganda has well-designed volunteer programs, such as VHTs, expert clients, and health unit management committees. Care for patients with chronic conditions can be improved by strengthening these programs through such measures as: 1) expansion to all areas of Uganda, 2) training and coaching volunteers as knowledgeable partners in chronic conditions care and disease prevention, and 3) prioritizing resources to keep health workers and volunteers motivated and effective. Other national programs, including HIV counseling and testing and standard national policies and guidelines for HIV care, are foundational to chronic care management.
- 4. Educate, coach, and support patients, communities, and health care providers** so they can carry out their roles effectively. This can include: 1) training patients and health care providers to work as teams to deliver chronic care and prevention strategies; 2) delivering community education—through radio announcements, television campaigns, school programs, posters and informational pamphlets—so the public understands and desires prevention and care for chronic conditions; and 3) sustaining this effort through partnerships with schools in health education (medical schools, clinical officer schools, nursing schools, etc.) and developing a required chronic care curriculum.
- 5. Develop an effective health information system** that will: 1) integrate all levels and types of care into one health record, 2) allow providers and supervisors to see the health outcomes of individual patients and their catchment populations, and 3) generate data for the MOH to use at all levels to evaluate the effectiveness of its programs and make changes based on accurate information.

Another product of the meeting was a revised Catalog of Potential Changes to Improve Care for Chronic Conditions (see **Appendix E**), which can be used to strengthen each component of the proposed Uganda chronic care model. These changes will help move from a care model that is more appropriate for acute conditions to one that works better for providing care for patients with chronic conditions. Many of these concepts are already in place in various settings in Uganda. The package is a work-in-progress, and further detail will be added in the future.

VII. References

National Health Service Modernisation Agency. 2002. "Improvement Leaders' Guides: General Improvement Skills. ILG 1.2. Process Mapping, Analysis and Redesign." Available at http://www.institute.nhs.uk/index.php?option=com_joomcart&Itemid=194&main_page=document_product_info&cPath=65&products_id=295.

WHO (World Health Organization). 2002. "Innovative Care for Chronic Conditions: Building Blocks for Action." Geneva. Available at <http://www.who.int/diabetesactiononline/about/icccreport/en/>.

WHO. 2004. "The 3 by 5 initiative: Integrated Management of Adolescent and Adult Illness (IMAI) modules. Geneva. Available at <http://www.who.int/3by5/publications/documents/imai/en/>.

VIII. Appendices

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Appendix A: Chronic Care Design Meeting and Conference Participant List

Chronic Care Design Meeting

MOH Uganda

Jacinto Amandua, Commissioner Clinical Services
Hudson Balidawa, National Coordinator Capacity Building
Eric Ikoona, National TB/HIV Coordinator – AIDS Control Programme
Apolo Kansime, Senior Medical Officer in charge of Home-based Care
Godfrey Kayita, Program Officer – HIVQUAL International
Augustine Muhwezi, National Quality of Care Coordinator
Elizabeth Namagala, National Coordinator, ART
Norah Namuwenge, Program Officer in Charge of Monitoring and Evaluation
Ario Alex Riolexus, Program Officer, Policy Development
Benson Tumwesigye, National Coordinator for HIV counseling and testing
Anne Wandera, Senior Principal Nursing Officer

USAID

Jacqueline Calnan, Project Management Specialist, USAID Uganda
James Heiby, Health Officer, USAID, Washington, D.C.

URC Bethesda

Katie Donohue, Project Coordinator for Global Initiatives
Marianne Drowne, Executive Assistant to M. Rashad Massoud
Suzanne Gaudreault, Senior Advisor for HIV/AIDS, TB, Malaria and Other Infectious Diseases
Kathleen Hill, Senior Technical Advisor
Whitney Isenhower, Communications Assistant
M. Rashad Massoud, USAID Health Care Improvement Project Director and Senior Vice President, Quality & Performance Institute
Ram Shrestha, Senior Quality Improvement Advisor, Community Health and Nutrition

URC Uganda

Deborah Asio, Finance and Administration Manager
Esther Karamagi Nkolo, Program Coordinator
Robert Kyeyagalire, Research and Information Officer
Nigel Livesley, Regional Director, East Africa
Anthony Musisi, Deputy Chief of Party
Morris Odyero, Driver
Martin Ssendyona, Senior Medical Officer in the Quality Assurance Department

Partners and Consultants

Bruce Agins, Medical Director of the New York State Department of Health AIDS Institute, New York, N., USA
Brandon Bennett, IHI, Improvement Advisor, Boston, MA, USA
Connie Davis, Connie L. Davis Health Services, Ltd., British Columbia, Canada

Jeffery Heck, Associate Dean of The University of North Carolina Medical School Asheville Regional Campus, Asheville, NC, USA

Kedar Mate, Content Director, IHI, Durban, South Africa

Kathy Reims, Chief Medical Officer at CSI Solutions, Denver, C.O., USA

May 31, 2010 Chronic Care Conference

Adeodata Kekitiimwa, Baylor-Uganda

Ros Kent, Mildmay, Uganda

Herbert Kisamba, Entebbe Hospital, Uganda

Dan Kyengera Kisitu, Luwero, Health Center IV, Uganda

Emmanuel Luyinw, Mildmay, Uganda

Ahmed Matoyu, Kayunga Hospital, Uganda

Milly Katana New Partners Initiative Technical Assistance Project/John Snow, Inc. (JSI), Uganda

Emmanuel Mukwadhanga, Kangulamira Health Center, Uganda

Victor Musiime, Joint Clinical Research Center, Uganda

Diriisa Musisi, Kayunga Hospital, Uganda

William Musoke, Mildmay, Uganda

Moses Muwanga, Entebbe Hospital, Uganda

Florence Nagawa, National Forum of PLHA Networks in Uganda (NAFOPHANU)

Rita Nalwadda, WHO, Uganda

Grace Nantege, NAFOPHANU

Neriah Rugarama, NAFOPHANU

Moses Wakabi, Entebbe Hospital, Uganda

Appendix B: Group Work: Patient Journey Mapping Exercise

ADAPTED FROM: National Health Service Modernisation Agency (2002).

AIM OF THE EXERCISE: For the site your group visited, create an accurate picture of what happens now with the care for ART patients.

Starting point for the journey: Diagnosis

End point for the journey: On treatment through more than one encounter with the health care team and community supports

Steps:

- Take a few moments to think about the key steps in the patient's journey as it exists now, beginning at the starting point.
- As a group, list the key steps in the ART patient's journey, thinking about who provides what to the patient. All members of the group can participate in writing steps. Each step goes on a separate Post-It note (i.e., "register the patient" goes on one Post-It; it is not necessary to state that registering the patient means greet the patient, ask for interval history, and collect demographic information).
- With guidance from the group, the team will place the Post-Its with steps in order on the poster paper to map the journey. All members of the team may be standing around the map during this part of the mapping. Avoid trying to address problems or "fix" the map at this point.
- Keep adding steps until everyone is satisfied that all the key steps have been identified.
- Add arrows between the steps once the map is agreed on.
- Once the you have drawn your map, analyse it:
 - Does the map represent what actually happens for patients right now?
 - Count the number of steps in the process.
 - Count the number of different staff members the patient sees.
 - Mark with a W and count the number of steps where a patient has to wait.
 - Estimate the time it takes the patient to take the journey.
 - Mark with a V the steps that have value to the patient and count them. How many steps have value out of the total number of steps?
 - What are problems in the process for the patient?
 - Where are the problems in the process for the staff?
 - What are the opportunities for improvement?
- Summarize the key points you will make in your group presentation on Friday and elect a group member (or members) to present your patient journey.

An example of a "Patient Journey Map" is included on the following page.



“Patient Journey Map” created after a design meeting group’s site visit to Entebbe Hospital. It shows the steps a patient living with HIV takes to receive care during a hospital visit. Photo by Marianne Drowne, URC.

Appendix C: Challenges to Providing Chronic Care in Uganda and Possible Solutions

Key Player	Challenges	Solutions
Patient	Taking medication on time	Use timers (church bells, radio) and have children and other family members remind patient.
	Staying informed and aware of condition and its concerns	Using mass media—an important information source for clients and health workers, church leaders, and expert clients in some areas.
	Staying mentally well	Join PLWHA peer support groups. Seek support from trusted family members and friends.
	Maintaining personal health	Manage a personal garden, eat well, avoid smoking and drinking alcohol, use protection during intercourse, and promote and practice family planning.
	Overcoming stigma	Serve as an advocate/voice in the community. Visit clinics and join groups that keep private appointments and meeting places for individuals with chronic conditions.
Family members	Maintaining patient's mental well-being and supporting self-management	Ensure a strong relationship with patient
	Caring for patient's physical health and supporting his/her self management	Ensure patient has access to nutritious foods, takes medications on time, and keeps clinic appointments.
	Keeping patient active and engaged in the community	Help link patient to community support structures, groups, etc. Join an appropriate support group (i.e. one that is open to people affected by (as well as infected with) a chronic condition.
	Supporting patient's participation and appointments	Remind patient and/or escort him/her to clinic appointments and support group meetings.
Expert clients	Complying with clinic and medical guidelines	Train and instruct on role. Give medical trainings (i.e., HIV testing, giving ART, etc.) if feasible
	Motivating (people want monetary compensation)	Provide compensation: This can include things such as reimbursing travel, providing food, drink, or a recognition/gift if money is not available.

Village health (VHTs) and community management teams	Motivating	Provide compensation, such as reimbursing travel, providing food or drink or a recognition/gift if money is not available.
	Training adequately	Continue trainings and emphasize VHTs' rights and roles.
	Supporting traditional healers and some who relay unofficial medical information and treatment not approved by the medical system	Train traditional healers and incorporate them into the health system. Advise patients on the differences between traditional and clinical care.
Community organizations that support volunteers and undertake activities to assist PLWHA	Successfully collaborating with MOH, NGOs and nonprofit organizations in the community	Work with faith-based organizations, but check into cost first.
	Transferring money between different system levels	Link all groups together (expert patients, VHTs, community management teams, community organizations, etc.).
	Lacking health facility resources to support community-based follow-up of patients in government-supported sites	Liaise with community organizations to carry out patient follow-up.
Clinicians/health center and hospital staff	Managing data	Use appointment books to track patients and their appointment adherence.
	Coping with limited trained staff	Ensure chronic care training in medical schools to ensure health workers learn of this issue and how to successfully approach it in their work.
	Properly diagnosing and treating patients	Early diagnosis and linkage to care centers for patients will lessen burden of chronic care if patients are started on care early.
	Strengthening intra-facility referral	Strengthen clinical care coordination by knowing who patients visit for care and keeping a proper appointment system.
	Patients lost to follow-up	Centers should be proactive instead of reactive when patients miss appointments (prevent patients lost to follow-up rather than trying to recoup patients already lost).
	Patients feeling unsupported thus not adhering to appointments/returning to clinic	Health workers should address depression and patients' emotional changes to keep them returning to clinic.
	Adapting to different care levels at different facilities (some lack proper lab and testing equipment)	Expand quality improvement (QI) interventions to all facilities since data show they are better equipped to handle chronic care.
	Having multiple ways for health workers to interact with patients in all areas	Establish retention policies for medical workers in hard-to-reach areas and create job aids, standard operating procedures, policy guidelines for chronic care, etc.
Policy-makers	Ensuring an adequate workforce capacity to handle chronic care	Create health information systems to monitor workforce capacity.
	Ensuring care coordination among sites and across system levels	Clearly define roles and job expectations in policy and translate this to set standards.
	Ensuring sufficient human resources	Develop policy and guidelines on task shifting.

Lacking system support so facilities are not well equipped and prepared to handle chronic care	Track stocking and supply chain management.
Experiencing inadequate coordination and implementation of care	Note necessary and unnecessary tasks for proper chronic care and keep facility work plans on file.
Having difficulty implementing a community approach in facilities with little funding and weak documentation	Reduce disparities by identifying the most vulnerable populations and targeting them first.
Having health facility staff who cannot stay abreast of current care concerns and issues	Provide continuous education and training, monitor and evaluate systems, and provide coaches and mentors.
Staff lacking understanding of what they can do for chronic care	Implement and make available a basic care package.
Uninformed and unsupportive general public toward chronic care; stigma among the public	Have media sources disseminate and provide information to patients and the public to help reduce stigma.
Funding new systems and keeping them on track	Keep track of costs.
Experiencing documentation that is redundant, with multiple reports with the same information for different support partners	Coordinate information and collaborate with other key players to produce fewer reports for the same purposes that can be viewed by multiple support partners.
Experiencing a disconnect between system and community levels	Ensure strong collaboration with community organizations such as NGOs, nonprofits, etc. through connections, contacts, and communication at the ground level.

Appendix D: Synthesis of May 31 Conference Group Work

PATIENT	
How the patient can help ensure he/she lives positively with a chronic condition, such as HIV	
Area addressed/resource to support care	Examples of what a patient can choose to do to aid this care
Physical health	<ul style="list-style-type: none"> • Adhere with ART; possibly receive a longer term drug supply. • Keep good nutrition; prevent new HIV infections. • Comply with treatment and keep a treatment plan, schedule, and medical appointments. • Ensure access to appropriate care. • Adhere to healthy habits, such as not smoking, avoiding alcohol, and moderate exercise (walking).
Mental health	<ul style="list-style-type: none"> • Accept HIV-positive status (overcome self-stigma). • Be responsible and disclose status; join peer support groups. • Accept needed behavior changes and reinforce positive behavior. • Empower other patients to seek quality care. • Seek advice from expert or informed patient(s).
Communication	<ul style="list-style-type: none"> • Maintain communication with provider, VHTs, community health workers (CHWs), and other patients. • Obtain information on self-management care. • Ask questions if you don't understand something. • Inform provider about problems early; give provider feedback.
Education and information	<ul style="list-style-type: none"> • Be knowledgeable and informed about virus and condition. • Seek information about the condition—be proactive and ask questions. • Know what the system can and cannot provide. • Use media for information gathering and sharing. • Be an advocate/voice for PLWHA and raise awareness.
Financial assistance	<ul style="list-style-type: none"> • Save money or buy insurance for emergency medical needs. • Set aside transportation funds. • Engage in income-generating activities (IGAs), perhaps with a peer support group.

COMMUNITY AND FAMILY	
How the community and family can assist and care for patients with chronic conditions, such as HIV	
Area addressed/resource to support care	Examples of what the community and family can choose to do to aid this care
Physical health	<ul style="list-style-type: none"> • Support patient adherence with drug regimen and appointments; take patient to clinic (if fearful). • Ensure availability of ARVs. • Provide support to patient for pediatric HIV. • Provide a conducive and clean environment (help patient maintain proper hygiene and ensure patient has clean drinking water). • Advise about healthy behaviors that prevent other chronic conditions (i.e., encourage not smoking or drinking alcohol). • Get tested for HIV and maintain own personal health.
Mental health	<ul style="list-style-type: none"> • Organize peer support group and/or encourage patient to join one. • Support development of competencies for family support. • Support patient's disclosure of his or her HIV status. • Accept the patient's status and condition (oppose stigma). • Provide spiritual and psychosocial support; treat patient kindly, fairly, and with equanimity. • Prevent gender discrimination (i.e., women who may be stigmatized and/or prevented from accessing care). • Provide/refer couple counseling to reduce stigma. • Provide spiritual, political, cultural, moral, and social support. • Counsel and encourage husbands and other family members to get tested.
Communication	<ul style="list-style-type: none"> • Encourage an open and supportive environment that facilitates communication about HIV and its challenges. • Support age-appropriate education of infected children, including disclosure of status when appropriate. • Participate in or collaborate with health management committees. • Refer new patients to proper care centers. • Maintain referrals and linkages with the health facility and community organizations (VHTs and CHWs).
Education and information	<ul style="list-style-type: none"> • Encourage patient to avoid risk of infecting others. • Refer people for testing and provide counseling. • Conduct community outreach. • Ensure education and linkages with religious and cultural community leaders. • Support patient with materials, documents, and sources of information about how to cope with HIV and other chronic conditions. • Educate community that HIV and other chronic conditions are treatable. • Support community workers in collecting information for community members and patients. • Participate in planning awareness sessions and advocate for patients in the community. • Stabilize VHT concept; assist family members in helping patient prepare and plan for what to do (and have in order) after the patient is gone.

COMMUNITY AND FAMILY	
How the community and family can assist and care for patients with chronic conditions, such as HIV	
Area addressed/resource to support care	Examples of what the community and family can choose to do to aid this care
Financial assistance	<ul style="list-style-type: none"> • Ensure patient has adequate food and eats a well-balanced diet. • Encourage and seek opportunities for patients to participate in IGAs. • Provide resources for IGAs (i.e., give seeds for a community garden, buy or donate animals for raising and selling, etc.). • Ensure transportation funds and systems are available for patient to seek care. • Help community pool funds for patients.
Infrastructure	<ul style="list-style-type: none"> • Address challenge of keeping motivated volunteers who work for free, e.g., pay them based on education, experience, etc.). • Connect with local organizations and NGOs for support. • Set up programs and talk to appropriate facilities about giving tokens, discounts, etc. for reduced transportation, food, and other work-related costs. • Ensure volunteers are not exploited (do not make them work long, unreasonable hours).

HEALTH CARE SYSTEM and PROVIDERS	
How the health care system and providers can help better care for the increasing number of patients with chronic conditions, such as HIV	
Area addressed/resource to support care	Examples of what the health care system and providers can choose to do
Physical health	<ul style="list-style-type: none"> • Assure availability of drugs and services at each visit. • Improve lab services. • Shift to also deliver care at lower-level facilities (decentralization). • Give nurses a greater role in providing treatment. • Improve access to care through outreach and home-based care. • Ensure continuous drug availability. • Counsel patient on proper nutrition and ensure he or she eats a well-balanced diet and meets his or her vitamin, protein, and energy nutrition needs. • Counsel patient about healthy behaviors (i.e., no smoking and drinking alcohol).
Mental health	<ul style="list-style-type: none"> • Mobilize clients to form and join peer support groups and link them with resources. • Counsel patients and be available for emotional support (be sure to establish personal boundaries).
Communication	<ul style="list-style-type: none"> • Emphasize low-level facilities that are linked with the community. • Develop an effective referral system. • Give community input and be an advocate during campaigns. • Maintain partnerships with private sector and special interest organizations (e.g., women and youth organizations). • Provide guidelines and ensure providers are knowledgeable of conditions. • Ensure clear communication of how referral system works, what care is available, and what patient must do to remain healthy.
Education and information	<ul style="list-style-type: none"> • Develop chronic care guidelines and clinic sessions. • Emphasize prevention in health systems—not just treatment. • Improve linkages between facilities and communities by collecting, analysing, and reporting information. • Strengthen partnerships with community organizations, groups, etc. that promote participatory decision making (i.e., sharing ideas from different parties and building consensus). • Help community build capacity to manage chronic conditions. • Map out referrals and linkages and provide feedback from referrals made. • Build health workers' capacity in information management, infrastructure, and laboratory work. • Provide chronic care policy guidelines (i.e., essential drug lists at hospitals often lack drugs for chronic conditions). • Communicate HIV prevention steps (condoms and family planning). • Implement provider referral system (external and internal, PMTCT, etc.) with proper tracking.
Financial assistance	<ul style="list-style-type: none"> • Provide insurance for individuals with chronic conditions. • Ensure services are funded and space and equipment are available. • Implement sliding-scale cost sharing.

HEALTH CARE SYSTEM and PROVIDERS	
How the health care system and providers can help better care for the increasing number of patients with chronic conditions, such as HIV	
Area addressed/resource to support care	Examples of what the health care system and providers can choose to do
Infrastructure	<ul style="list-style-type: none"> • Build and continue to build the capacity of human resources. • Ensure fair allocation of resources. • Coordinate NGOs to ensure they are properly distributed to ensure equity of services. • Engage lay people: policy, training, and task shifting; build health workers' capacity and commitment through trainings. • Ensure adequate staffing at all levels. • Ensure monitoring and evaluation of system, structure, workplace, workers, etc. • Train health workers about HIV care, which also reduces stigma, and how to increase availability of drugs and ARVs. • Build and ensure good governance and leadership.

Appendix E: Catalog of Potential Changes to Improve Care for Chronic Conditions¹

PATIENT	
Change concept: Take care of the illness using core self-management skills	
Action Steps	Examples of what a patient can choose to do
Learn and use problem-solving techniques.	<ul style="list-style-type: none"> • Participate in one-on-one or cluster teaching in clinic. • Interact with expert patients (formal and informal). • Join peer support groups. • Learn from their personal experience through repeated attempts and lessons learned. • Work with their family and community supports. • Understand that they are unique and customize ideas to their own life.
<ul style="list-style-type: none"> • Make day-to-day decisions for management and take action to improve health. • Use medication reminders. • Have a plan for managing condition. • Monitor symptoms or condition indicators. • Use medication reminders. • Apply information to lifestyle. 	<ul style="list-style-type: none"> • Use radio as a reminder to take pills. • Use phone alarm to remind them to take drugs. • Use patient-held card, which has adherence calendar. • Work with schools and parents (children). • Work with treatment supporters. • Use personal triggers as a reminder. • Use feedback mechanisms like weight, test results, symptom monitoring. • Practice hygiene and infection control (TASO, Program for Accessible Health, Education and Communication, Joint Clinical Research Centre, Mildmay). • Use safe sex practices. • Set personal goals.
<ul style="list-style-type: none"> • Find and use resources. • Know when and where to seek health information. • Identify reliable information sources. • Work with community groups. • Learn to navigate the health care system. 	<ul style="list-style-type: none"> • Listen to radio, including phone-in talk shows and TV programs. • Read posters. • Use cell phone messages. • Work with the VHT. • Use the Internet for information on drugs and disease. • Seek churches that offer information. • Know where to find health care workers for information. • Avail patient associations that pool resources.
<ul style="list-style-type: none"> • Partner with health care professionals. • Align with a health care team. • Include family and friends in visits as needed. • Bring questions to visits. • Tell health care professionals if something is unclear. • Share any barriers that might prevent taking medications. • Provide feedback on how treatment is working. 	<ul style="list-style-type: none"> • Interact with expert patients in the facility and community. • Join peer support groups and learn from others' personal experience through repeated attempts and lessons learned. • Work with their family and community supports. • Use treatment supporters.

¹ Dr. Kathy Reims and Ms. Connie Davis developed this Catalog for discussion at the Chronic Care Design Meeting.

PATIENT	
Change concept: Maintain important daily activities	
Action Steps	Examples of what a patient can choose to do
Maintain and/or adjust life roles and identity.	<ul style="list-style-type: none"> • Participate in one-on-one teaching in clinic. • Interact with expert patients. • Join peer support groups, including groups that have peers with multiple health conditions. • Learn from peers' personal experience. • Work with their family and community supports. • Work with treatment supporters. • Discuss family members' roles with them and adjust as needed. • Work within social networks.
Participate in personally meaningful activities.	
Maintain supportive relationships with families, friends, and the community.	
Change concept: Manage emotional changes	
Action Steps	Examples of what a patient can choose to do
Identify anger, fear, frustration, and depression and develop self-care approaches.	<ul style="list-style-type: none"> • Work with organizations that address psychosocial issues.. • Participate in one-on-one teaching in clinic. • Interact with expert patients. • Join support groups. • Learn from peers' personal experience. • Work with their family and community supports. • Participate in mixed chronic care clubs to fight stigma associated with illnesses.
Learn to deal with stigma.	
Plan for the future.	<ul style="list-style-type: none"> • Work with community-based organizations and NGOs, e.g., legal aid. • Participate in one-on-one teaching in clinic. • Participate in a will-writing program. • Plan reproduction. • Plan for care of dependents in case of illness or death.
Maintain supportive relationships with families, friends, and the community.	<ul style="list-style-type: none"> • Work with supportive church groups. • Participate in one-on-one teaching in clinic. • Interact with expert patients. • Join support groups. • Learn from peers' personal experience. • Work with their family and community supports.
Change concept: Engage in health promotion and prevention activities	
Action Steps	Examples of what a patient can choose to do
Consider and adopt activity, hygiene, and dietary changes to achieve health care goals.	<ul style="list-style-type: none"> • Participate in IGAs. • Have a garden. • Work with counselors on exercise. • Attend nutrition education. • Avoid smoking, alcohol, and drugs. • Engage in positive prevention programs. • Use condoms and practice safe sex. • Sleep under a bed net.
Plan pregnancies in light of health considerations.	<ul style="list-style-type: none"> • Work with health care workers. • Use birth control. • Learn about fertility treatment.

FAMILY	
Change concept: Support the patient to take care of the illness	
Action Steps	Examples of what families can choose to do
Assist the patient with problem solving about his or her illness to make day-to-day decisions for managing the condition.	<ul style="list-style-type: none"> • Interact with expert patients (formal and informal) and their families. • Work with community supports. • Understand that the patient's situation is unique, and customize ideas to fit his or her situation.
<ul style="list-style-type: none"> • Help the patient make day-to-day decisions to manage the condition. • Have a plan for managing the condition. • Monitor symptoms or condition indicators. • Use medication reminders. • Apply information to lifestyle. 	<ul style="list-style-type: none"> • Become a treatment supporter. • Support patient to find reminder systems that work or remind the patient directly to take his or her their pills and treatments. • Work with schools. • Understand and use feedback mechanisms like weight, test results, and symptom monitoring. • Practice hygiene, infection control. • Use safe sex practices. • Help the patient to set goals.
Learn about and encourage use of resources that will help the patient.	<ul style="list-style-type: none"> • Listen to the radio, including phone-in talk shows and TV programs. • Read posters. • Use cell phone messages. • Work with the VHT. • Use the Internet for information on drugs and disease. • Seek churches that offer information. • Know where to find health care workers for information. • Participate in patients/family associations that pool resources.
Attend health care visits with the patient.	<ul style="list-style-type: none"> • Interact with expert patients in the facility and community. • Support the patient to ask questions and get answers at visits. • Participate in one-on-one teaching in clinic with the patient. • Participate in mixed chronic care clubs to reduce stigma associated with illnesses.
Change concept: Help the patient maintain important daily activities	
Action Steps	Examples of what families can choose to do
Maintain and/or adjust life roles and identity.	<ul style="list-style-type: none"> • Participate with the patient in one-on-one teaching in the clinic. • Interact with expert patients. • Encourage the patient to join peer support groups, including groups that have peers with multiple health conditions. • Help the patient learn from peers' personal experience. • Work with the patient and community support. • Become a treatment supporter. • Discuss roles and adjust as needed. • Work with social networks.
Participate in personally meaningful activities with the patient.	
Maintain supportive relationships with the patient, friends, and community.	
Change concept: Support the patient who experiences emotional changes	
Action Steps	Examples of what families can choose to do
Recognize anger, fear, frustration, and depression and help the patient use self-care approaches.	<ul style="list-style-type: none"> • Work with organizations that address psychosocial issues. • Participate with the patient in one-on-one teaching in clinic.

FAMILY	
Learn to deal with stigma.	<ul style="list-style-type: none"> • Interact with expert patients. • Encourage the patient to join support groups. • Learn from the personal experience of members of those groups. • Work with their family and community supports.
Plan for the future.	<ul style="list-style-type: none"> • Work with community-based organizations and NGOs, e.g., legal aid. • Participate in one-on-one teaching in the clinic. • Participate in will-writing programs. • Plan reproduction. • Plan for care of dependents in the event of illness or death.
Maintain supportive relationships with the patient, friends, and community.	<ul style="list-style-type: none"> • Work with supportive church groups. • Participate in one-on-one teaching in clinic. • Interact with expert patients. • Join support groups. • Learn from peers' personal experience. • Work with peers' family and community supports.
Advocate for the patient to get help with psychosocial issues.	<ul style="list-style-type: none"> • Ask the health care team what is available to help the patient. • Help the patient attend visits at referral centers.
Change concept: Engage in health promotion and prevention activities with the patient	
Action Steps	Examples of what families can choose to do
Consider and adopt a healthy lifestyle, including physical activity, hygiene, decreasing risk of sexually transmitted diseases, managing infections, and dietary changes to achieve health care goals.	<ul style="list-style-type: none"> • Participate in IGAs. • Have a garden. • Work with counselors on exercise. • Attend nutrition education. • Avoid smoking, alcohol, and drugs. • Participate in positive prevention programs. • Use condoms; practice safe sex. • Sleep under a bed net.
Plan pregnancies in light of health considerations.	<ul style="list-style-type: none"> • Work with health care workers. • Use birth control. • Consider fertility treatment.

HEALTH CARE TEAM	
Change concept: Design care delivery to meet patient needs	
Action Steps	Examples of what health care teams can choose to do
Establish functional teams (A team includes all individuals who participate in patient's care, including expert patients, volunteers, nurses, clinicians.).	<ul style="list-style-type: none"> • Have regular team-meetings to work on roles and specific tasks. • Task shift to lower-level providers for routine, non-complex tasks. • Establish standard protocols to move work away from the provider. • Use effective team communication methods. • Flowchart to understand the team roles.
Optimize access.	<ul style="list-style-type: none"> • Outreach (e.g., provide ARV services locally). • Offer flexible hours. • Offer flexible fees.
<ul style="list-style-type: none"> • Use planned interactions to support evidence-based care. • Manage patients proactively. 	<ul style="list-style-type: none"> • Give patients appointments for drug pick-ups and clinician visits. • Implement provider-initiated testing. • Offer home visits for patients who need them. • Avail mobile phone technology for communicating with patients. • Use group visits for clinical care.
Promote linkages of services	<ul style="list-style-type: none"> • Ensure new patients are appropriately oriented to new facility,

HEALTH CARE TEAM	
within the facility.	<p>including different service areas (e.g., lab, TB care, PMTCT, etc.).</p> <ul style="list-style-type: none"> • Consider “expert patient” orienters and facilitators for new and returning patients. • Use media, including posters and videos, when possible, to orient new patients. • Promote standardized communication mechanisms between facility service areas (e.g., use a standard, intra-facility paper form to help staff direct patients/caretakers to appropriate services).
Promote coordination within the facility.	<ul style="list-style-type: none"> • Coordinate teams that provide care collectively. • Coordinate facility administration work. • Coordinate with district-level staff.
Retention in care: Ensure regular, proactive follow-up and tracking of patients who miss appointments.	<ul style="list-style-type: none"> • Maintain appointment diary in clinic. • Work with clients to reduce deterrents to follow up (e.g., long waits, disrespectful care, medicine stock outs). • Develop process to track missed appointments and ensure patient contact (assign task to specific team member, e.g., patient expert). • Use phone reminders of upcoming visits and for missed appointments. • Make better use of mobile phones for patient communication/follow-up. • Implement home visits. • Have expert patients follow up with patients who miss visits. • Have geographically clustered patient groups follow up on same schedule so that individual members of group can promote communication and follow-up for other members. • Have patient groups identify key obstacles and test changes in service delivery that can reduce missed appointments. • Consider modifying follow-up frequency protocols to be responsive to patient needs and realities. • Orient and educate patients on agreed processes for follow-up in event of missed appointment. • Orient patient on agreed process for follow-up of an acute illness.
Understand and proactively manage subsets of patients (adolescents, TB/HIV patients, pregnant women).	<ul style="list-style-type: none"> • Group visits • Special clinics
Integrate mental health into routine practice.	<ul style="list-style-type: none"> • Integrate depression screening tools into routine visits to proactively diagnose and treat depression.
Change concept: Support decisions with evidence	
Action Steps	Examples of what health care teams can choose to do
Embed evidence-based guidelines into daily practice.	<ul style="list-style-type: none"> • Condense established MOH guidelines into user-friendly intervention packages structured around regular visit types that occur in every patient’s chronic care journey. • Develop simple job aids. • Develop checklists tailored to specific visit types. • Use standard patient monitoring cards that remind providers of key elements of package.
Build provider capacity to deliver chronic illness care.	<ul style="list-style-type: none"> • Offer case-based, continuing medical education with follow-up supportive supervision.
Use standing orders and protocols to ensure delivery of evidence-based interventions and prevent errors.	<ul style="list-style-type: none"> • Have nurses order routine tests.

HEALTH CARE TEAM	
Share treatment expectations with patients, expert patients, and organizations that represent patients.	<ul style="list-style-type: none"> • Provide a patient booklet about care expectations. • Communicate reasons for and value of various treatment actions to patient. • Provide take-home patient education materials. • Support patient education in peer groups.
Change concept: Use clinical information systems at the point of care	
Action Steps	Examples of what health care teams can choose to do
Establish a patient information system that can be used to plan and monitor individual care.	Use blue ART cards.
Make information available about specific patient populations when needed (e.g., be able to contact all patients who are taking a specific medication that is recalled or someone who has not returned for follow-up).	
Use data to guide efforts to improve quality of patient care in the clinic.	
Change concept: Support self-management for chronic conditions, prevention, and risk reduction	
Action Steps	Examples of what health care teams can choose to do
Adjust care to respond to patient and family values and expressed needs.	<p>5 “A”s:</p> <ul style="list-style-type: none"> • Assess patient priorities/clinical status and behaviors/knowledge. • Advise patient per evidence-based guidelines. • Assist patient to identify barriers and solutions to proactive self-management. • Arrange specific follow-up for patient using facility and community resources to support patient’s ongoing self-management. • Adjust care and monitor patient to improve patient experience.
Partner with patients to understand their central role in managing their health.	<ul style="list-style-type: none"> • Have peers provide regular health education in outpatient department settings while patients wait to see clinicians. • Provide literature on disease, drugs, and side effects. • At a health maintenance exam, state “Your health is in your hands. We are here to help you be as healthy as you can be.” • Let patient and family know that self-monitoring provides important information that they and other health care team members can use to make good care decisions. • Carry exercise books.
Use effective self-management support strategies, including goal setting, action planning, problem solving, and follow-up.	<ul style="list-style-type: none"> • Use patient-monitoring tools, such as calendars for testing intervals. • Have expert patients interact with other patients in waiting room to share experiences and respond to questions and barriers. • Have health professional ask the patient to repeat instructions given to patient. • Use personal action plans.
Organize and integrate internal and community resources to provide ongoing self-management support to patients	Use treatment supporters, community peers, support groups, and network support agents.

HEALTH CARE TEAM	
Provide information about condition and its treatment.	<ul style="list-style-type: none"> • Use peer teaching groups. • Provide a post-test and diagnosis counseling.

COMMUNITY PARTNERS	
Change Concept: Develop relationships with local care team	
Action Steps	Examples of what community partners can choose to do
Mobilize community groups to implement strategies to prevent disease or minimize complications.	Have multiple community groups with prevention and testing programs.
Work with the care team to extend the capacity of care provision.	Engage VHTs, network support agents, etc.
Teach lay workers how to implement standardized, effective interventions to support patients in the community.	Encourage the involvement of VHTs, expert patients, and the health unit management committee.
Change Concept: Support patients to live successfully in their community	
Action Steps	Examples of what community partners can choose to do
Facilitate care adherence and eliminate barriers to care.	Support home-based care, VHTs, peer support groups, and expert patients.
Reduce stigma associated with care.	Involve the health unit management committee, expert patients, supportive churches, and national awareness campaigns.
Respect cultural differences and patient family choices.	
Support IGAs.	Facilitate a group of patients pooling funds to purchase supplies to make crafts to sell.
Change concept: Harmonize with local, district, regional, and national plans	
Action Steps	Examples of what community partners can choose to do
Contact district and gain approval.	<ul style="list-style-type: none"> • Have the health center and health unit management committee work together to develop a coordinated plan. • Use actual patient stories to communicate the message of the need for chronic care management at the community level.
Communicate and coordinate with district.	
Design a sustainable funding plan.	
Change concept: Design and use feedback mechanisms to improve program	
Action Steps	Examples of what community partners can choose to do
Collect data about the program's effectiveness.	Engage the community dialogue to assess satisfaction.
Use data for planning needed community resources and to improve existing programs.	

HEALTH CARE ORGANIZATION	
Change concept: Promote continuity and care coordination over time among sites and across health system levels (community, clinic, district hospital, regional hospital, etc.)	
<ul style="list-style-type: none"> • Develop and use referral/counter-referral guidelines and implementation strategies. • Communication mechanisms (provider/CHW) 	

HEALTH CARE ORGANIZATION	
<p>to provider when possible.</p> <ul style="list-style-type: none"> • Systems support for referral (transportation, financial). • Involve community (VHTs). • Tracking to ensure adherence with referral and follow-up. • Clear identification of geographic locus. • Mapping of services. • Capacity building for coordinated referral processes at community and facility levels. 	
<ul style="list-style-type: none"> • Coordinate acute and chronic care (including management of acute exacerbations of chronic conditions). • Integrate acute and chronic care services. 	
Build on existing successful models of care to develop, scale up, and roll out comprehensive chronic illness care.	
Standardize approach to chronic illness care across patient, community, and health care facilities.	
Change concept: Encourage quality through leadership and incentives	
Action Steps	Examples of what health care organizations can choose to do
Have senior leader provide clear support and campaigns for quality of care.	
Build on QI efforts to expand, further develop, and roll out across all service points.	Implement QI training program.
Link ongoing funding to effectiveness of community programs.	Have the district oversee community programs.
Create a unified system for program evaluation.	
Monitor and disseminate information about health status, health care system outcomes, and new models for care.	
Build the capacity for integration of chronic care into district and facility annual work plans.	
Change concept: Organize and equip health care teams	
Action Steps	Examples of what health care organizations can choose to do
<p>Build chronic care skills:</p> <ul style="list-style-type: none"> • Incorporate chronic care skills into educational continuum for health care workers (pre-service, in-service, coaching, and mentoring). • Build the capacity to integrate chronic care into district and facility annual work plans. • Integrate chronic care skills into supervision training. 	Build quality of care content into fellowship program.
Build facility staff's capacity to proactively manage supply chain.	Health center IV and hospital in Uganda
Provide adequate and appropriate facilities (space designed to support essential services).	
<ul style="list-style-type: none"> • Assure supply chain for pharmaceuticals, laboratory supplies, patient monitoring materials, and essential supplies. 	

HEALTH CARE ORGANIZATION	
<ul style="list-style-type: none"> Use national and district logistics management information systems for proactive supply chain management and prevention of stock out (including sufficient back-up stock). 	
Integrate chronic care skills into supervision training.	
Change concept: Use information systems	
Action Steps	Examples of what health care organizations can choose to do
<ul style="list-style-type: none"> Develop an information system that supports chronic care at the patient, population, and national levels. Have a unique patient number. 	<ul style="list-style-type: none"> Continue to develop the integrated chronic care patient card.
Expand patient-controlled information systems.	<ul style="list-style-type: none"> Use patient-held records. Use treatment cards.
Change concept: Support self-management and prevention	
Action Steps	Examples of what health care organizations can choose to do
Encourage patients to expand their role in decision-making, health-related behaviors, and self-management.	<ul style="list-style-type: none"> Disseminate and distribute guidelines. Guidelines on patient education and counseling.
Adapt self-management training materials for patients.	Provide materials in local languages.
Design easily understandable, accurate information for patients.	Provide patient education charts in local languages.

COMMUNITY	
Change concept: Raise awareness and reduce stigma	
Action Steps	Examples of what the community can choose to do
Build on HIV experience to deliver messages about other chronic conditions.	Use actual patient stories (testimonies) to communicate the message of the need for chronic care management at the community level.
Inform local leaders about burden of chronic illness and strategies for prevention.	Work with local councils, opinion leaders, women's groups, and religious leaders.
Change concept: Encourage better outcomes through leadership and support	
Action Steps	Examples of what the community can choose to do
Identify community leaders and bring them on board to support care for chronic conditions.	Work with local councils, opinion leaders, women's groups, and religious leaders.
Use recognized structures like a health unit management committee or parish and village development groups to advocate for better chronic conditions care.	Have women's groups advocate for cancer screening.
Encourage all leaders to align policies and practices to optimize chronic illness care.	Local ordinances to support healthy behaviors.
Change concept: Mobilize and coordinate resources	
Action Steps	Examples of what the community can choose to do

COMMUNITY	
Encourage local efforts for promotion, prevention, risk factor assessment, training of community health workers, and obtaining basic equipment and supplies.	
Encourage local leaders to raise funds and identify other resources to support screening, prevention, and improved management of chronic conditions.	Avail community systems.
Train informal providers to provide basic services and educate the community.	Avail expert patients.
Support communities to develop self-supporting initiatives for resource mobilization.	
Change concept: Expand services	
Action Steps	Examples of what the community can choose to do
Take an inventory of existing services.	
Eliminate redundancies and duplication in provision of services between health care organizations and community organizations.	

POSITIVE POLICY ENVIRONMENT	
Change concept: Strengthen partnerships	
Action Steps	Examples
Strengthen central coordination at the MOH to coordinate health partners.	<ul style="list-style-type: none"> Public-private partnerships Health partners advisory committee
Enhance connections with district, municipal and local governments and community entities	
Change concept: Support regulatory and legislative framework	
Create policies that support improvements in chronic illness care.	
Support changes in registration requirements and education to equip health care workers to deliver care to people with chronic conditions.	
Enact laws to protect rights of people with chronic care conditions.	
Protect health care institutions and workers with regulatory frameworks.	<ul style="list-style-type: none"> Single-use needles Masks to prevent transmission of respiratory illness
Change concept: Integrate policies	
Action Steps	Examples
Work across ministries such as health, education, defence, and others.	Multi-sectoral approach to HIV.
Update policies regularly based on needs assessments, priorities, and intervention strategies that work.	
Change concept: Provide leadership and advocacy	
Action Steps	Examples
MOH officials visibly support chronic illness care	

POSITIVE POLICY ENVIRONMENT	
MOH advocates for budget to support system changes for chronic care.	Ensure regular supply of commodities for chronic care.
Change concept: Promote consistent financing	
Base financing decisions on principles of equity and effectiveness to ensure adequate health care access and coverage for all segments of the population.	
Integrate funding across disease categories, levels of care, and care settings.	
Structure financing to be maintained over time.	
Change concept: Assure workforce capacity and capability for provision of chronic care	
<p>Promote adequate staffing level and support systems:</p> <ul style="list-style-type: none"> Promote implementation of health sector, human resources, motivation policy, and strategy plans that support staffing, human resources capacity building, and management for chronic care. Develop recruitment strategies (prioritizing “hard to reach” areas). Have a health care worker registry and monitoring at district and national levels aligned with strategies that support chronic conditions. Clearly define roles and job expectations for chronic conditions care in policy and translate into standards and minimum package of activities for each health worker cadre. Create retention incentive programs (e.g., post-graduate training incentives). Shift tasks and reduce unnecessary/ redundant tasks (e.g., expand role of experts clients; eliminate or reduce frequency of non-essential tasks such as frequency of blood pressure measurement). Promote group visits and self-management strategies to increase proactive self-management, maximize visit efficiency, and reduce visit volume (via reduced frequency of individual visits). 	<ul style="list-style-type: none"> Human resources for health policy Health sector strategic plan III Motivation policy and plan MOH “hard to reach” framework Task shifting
<p>Build chronic care skills:</p> <p>Incorporate chronic care skills into educational continuum for health care workers (pre-service, in-service, coaching, and mentoring).</p>	
<p>Develop health information systems that incorporate the following functions:</p> <ul style="list-style-type: none"> Tracking Mapping Monitoring Aggregation Reporting 	
Use health information system for quality improvement and national policy implementation and to communicate progress.	
Involve Ministries of Education and Health to upgrade curricula	
Change concept: Reduce disparities in care (equity and equality)	

POSITIVE POLICY ENVIRONMENT	
Action Steps	Examples
Conduct situational analysis to identify vulnerable populations who bear greatest burden of unmanaged chronic conditions (wealth, age, gender, geographic).	
Target interventions to identified vulnerable populations.	
Reframe partner expectations for coverage of clinic or district to guarantee access to standards of care.	
Create process for routinely analyzing data for disparities (disaggregation of data by gender and age and identified vulnerable groups).	
Assure standards of care are applied equitably across all populations.	<ul style="list-style-type: none"> • Equitable access to CD4 testing • Policy of equal access • MOH framework for “hard to reach” populations

USAID HEALTH CARE IMPROVEMENT PROJECT

University Research Co., LLC
7200 Wisconsin Avenue, Suite 600
Bethesda, MD 20814

Tel: (301) 654-8338

Fax: (301) 941-8427

www.hciproject.org