TECHNICAL REPORT

Applying the Chronic Care Model to Health System Design in Low-resource Settings: Lessons from HIV Improvement Interventions

DECEMBER 2013

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December 2013

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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.
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**Acronyms**

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
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<tbody>
<tr>
<td>AIDS</td>
<td>Acquired immunodeficiency syndrome</td>
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<tr>
<td>ART</td>
<td>Antiretroviral therapy</td>
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<td>ARVs</td>
<td>Anti-retroviral drugs</td>
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<tr>
<td>ASSIST</td>
<td>USAID Applying Science to Strengthen and Improve Systems Project</td>
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<tr>
<td>CBO</td>
<td>Community-based organization</td>
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<tr>
<td>CCM</td>
<td>Chronic care model</td>
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<tr>
<td>CHW</td>
<td>Community health worker</td>
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<tr>
<td>CIS</td>
<td>Clinical information system</td>
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<tr>
<td>CR</td>
<td>Community resources</td>
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<tr>
<td>DM</td>
<td>Diabetes mellitus</td>
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<tr>
<td>DS</td>
<td>Decision support</td>
</tr>
<tr>
<td>DSD</td>
<td>Delivery system design</td>
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<tr>
<td>EID</td>
<td>Early infant diagnosis</td>
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<tr>
<td>EP</td>
<td>Expert patient</td>
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<td>HCI</td>
<td>USAID Health Care Improvement Project</td>
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<tr>
<td>HCO</td>
<td>Health care organization</td>
</tr>
<tr>
<td>HIV</td>
<td>Human immunodeficiency virus</td>
</tr>
<tr>
<td>HRSA</td>
<td>U.S. Health Resources and Services Administration</td>
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<tr>
<td>HTN</td>
<td>Hypertension</td>
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<tr>
<td>ICCC</td>
<td>Innovative Care for Chronic Conditions</td>
</tr>
<tr>
<td>ICF</td>
<td>Intensified case finding for tuberculosis</td>
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<tr>
<td>ICIC</td>
<td>Improving Chronic Illness Care project</td>
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<td>IHI</td>
<td>Institute for Healthcare Improvement</td>
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<td>IOM</td>
<td>Institute of Medicine</td>
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<tr>
<td>LMICs</td>
<td>Low- and middle-income countries</td>
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<td>MDGs</td>
<td>Millennium Development Goals</td>
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<td>MOH</td>
<td>Ministry of Health</td>
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<tr>
<td>MUAC</td>
<td>Mid-upper arm circumference</td>
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<tr>
<td>NCDs</td>
<td>Non-communicable diseases</td>
</tr>
<tr>
<td>OPD</td>
<td>Outpatient department</td>
</tr>
<tr>
<td>PCMH</td>
<td>Patient-centered medical home</td>
</tr>
<tr>
<td>PEPFAR</td>
<td>U.S. President’s Emergency Plan for AIDS Relief</td>
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<tr>
<td>PMTCT</td>
<td>Prevention of mother-to-child transmission of HIV</td>
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<tr>
<td>QALY</td>
<td>Quality-adjusted life year</td>
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<tr>
<td>QI</td>
<td>Quality improvement</td>
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<tr>
<td>SM</td>
<td>Self-management</td>
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<td>SMS</td>
<td>Self-management support</td>
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<td>URC</td>
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<td>USAID</td>
<td>United States Agency for International Development</td>
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<tr>
<td>USD</td>
<td>United States dollar</td>
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<tr>
<td>WHO</td>
<td>World Health Organization</td>
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EXECUTIVE SUMMARY

Developed in the mid-1990’s, the Chronic Care Model (CCM) has been one of the most widely applied and influential frameworks for improving health care to meet the needs of patients with chronic illnesses. The model considers four basic interlinked system components critical in providing good chronic illness care: 1) clinical information systems optimized to facilitate long-term disease management, 2) delivery systems designed to be efficient and proactive, 3) decision support to help providers exercise sound, evidence-based clinical judgment, and 4) self-management support to help patients negotiate the daily challenges and choices involved in providing good self-care. These components are embedded in two additional CCM components: 5) supportive health system leadership and 6) complementary community resources.

Due to its generalizability and to mounting evidence of its utility, the CCM has been used to enhance health systems in a multitude of settings, covering several different chronic conditions in the United States and other high-income countries. Reports on applications of the model in HIV treatment programs are limited but have produced encouraging results. In some instances the CCM is implemented in its entirety while in others, only specific components of the model are emphasized. Programs to improve self-management support (SMS) have been especially numerous. SMS interventions which go beyond simple patient education to helping patients to improve their behavioral and problem-solving skills and to build confidence, have been particularly beneficial. The CCM has been adapted and tailored to health systems across the globe and incorporated into broader health system frameworks which are more context-specific, such as the World Health Organization (WHO) Innovative Care for Chronic Conditions (ICCC) framework. While this adaptation of the CCM has informed high level policymakers and planners in low- and middle-income countries (LMICs) throughout the world, use of the CCM in facility-level improvement efforts has been limited.

Since 2009, the United States Agency for International Development (USAID), with funding from the U.S. President's Emergency Plan for AIDS Relief (PEPFAR), has supported activities to improve care for chronic conditions, primarily focused on HIV, through the USAID Health Care Improvement Project (HCI). An important early milestone in this effort was a Chronic Care Design Meeting held in Kampala, Uganda to explore how to improve care for HIV and other chronic conditions in Africa. Uganda was selected as the host of the meeting because it has been a leader in HIV care among African nations—exhibited by the country’s implementation of programs such as the Ministry of Health (MOH) Quality of Care Initiative in HIV and AIDS.

The meeting aimed to address chronic care for people living with HIV and other chronic conditions in Uganda and Africa. Some 50 participants—among them MOH officials; HCI staff and consultants; USAID, donor, and implementing partner representatives; and chronic care experts—convened May 26–28, 2010 to analyze current chronic conditions care in Uganda, visit facilities currently providing chronic conditions care, and discuss how it can be improved and adapted to provide better care for patients with long-term illnesses and medical conditions.

The meeting’s results were then presented at the opening day of a four-day health care improvement conference in Kampala that convened Ugandan health care providers and representatives from nine other African nations: Cote d'Ivoire, Nigeria, Rwanda, Kenya, Tanzania, Ethiopia, Malawi, South Africa, and Namibia. 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 would develop and test the principles of chronic conditions care through a demonstration project that would be implemented with support from HCI in one district in Uganda.

Following on the chronic conditions care demonstration in Buikwe District, in 2011 HCI began supporting the Ministry of Health and Social Welfare of Tanzania to introduce the CCM at 14 sites in two districts in the region of Morogoro. QI teams and health system officials elected to focus on patient
self-management support as the weakest and most critical component of their HIV care delivery systems.

HCI’s application of the CCM in Uganda and Tanzania has emphasized: 1) integration of CCM into essential primary care services and 2) improvement of core HIV treatment services. Applications of improvement science in Uganda to the integration of nutrition and palliative care have yielded important lessons about including essential primary care services in chronic conditions care. Changes developed by facility teams in these contexts were relevant to the CCM, which may therefore be a useful tool in further efforts to include and enhance these and other essential services in HIV care and treatment programs. Activities which have deliberately employed the CCM to enhance core care and treatment services include: the comprehensive application of the model in one district in Uganda and an initiative in two Tanzanian districts focused on improving patient self-management support. Both efforts yielded encouraging results and prompted the launch of a controlled study, currently underway in Uganda, to measure the impact of CCM implementation.

HCI-supported experiences to date, along with existing evidence from higher resource settings, suggest that the principles of chronic care as described by the CCM: 1) are so fundamental to the provision of high quality modern health care services for chronic illnesses that the model is as applicable in LMICs as it is in higher income countries; 2) are applicable in a variety of contexts, including the integration of primary care services such as nutrition and palliative care; and 3) have considerably greater impact when relevant components of the CCM are applied harmoniously at all levels of the health system.
I. INTRODUCTION

The last hundred years have yielded unprecedented advancements in medical science, leading to substantial improvements in the health and longevity of people accessing modern health services. The full capacity of modern medical interventions to improve human health is severely undermined, however, by economic constraints intertwined with insufficient identification of, and actions to remedy, fundamental weaknesses in health service delivery. In 1978, the Declaration of Alma-Ata launched the movement for global universal health care, defining a set of guiding principles, built around the provision of primary care, for addressing basic human health needs and social determinants of health.1 Alma-Ata emphasized equitable and efficient delivery of health services; promoted local ownership and community engagement; and placed equal emphasis on prevention as on treatment with rational investment of resources at all levels of care. Although this Declaration was widely misunderstood and criticized at the time, the values and vision it put forth have tremendously influenced subsequent global health policy and action. The Millennium Development Goals, established 22 years later, were in fact founded on the same values of social justice and community-sensitivity laid out by Alma-Ata. While population health is intimately tied to economic development, globalization and population growth continuously challenge low- and middle-income countries (LMICs) to expand access to and increase effectiveness of modern health care services. As countries struggle to respond to the mounting health needs of their citizens in the face of shrinking foreign assistance and competing national priorities, the necessity of developing affordable and innovative approaches to health system strengthening has never been greater.

For many years, global health programs focused largely on mitigating the detrimental effects of infectious diseases on populations, with considerable support provided for vaccination programs and for the development of systems designed for acute treatment of infectious diseases. Such systems are reactive, episodic, and are most effective at treating illnesses with an abrupt onset and a short duration. In contrast, chronic illnesses have a gradual onset and a long duration, and they are not generally curable. Health care interventions for chronic conditions are therefore not intended to cure but rather to prolong life and to enhance quality of life by maximizing functional status and minimizing distressing symptoms. Consequently, systems designed mainly to address acute illnesses are poorly equipped to meet the complex, long-term needs of people with chronic conditions.

It is estimated that by 2030 chronic diseases will account for 70% of the global burden of disease, and 65% of the global disease burden of chronic non-communicable diseases will occur in LMICs.2,3,4 In many LMICs, especially in sub-Saharan Africa, HIV is the first chronic condition to receive sufficient resources to achieve widespread implementation of treatment programs. The global response to the HIV/AIDS epidemic has produced some encouraging results, including a 20-fold increase in number of people accessing antiretroviral drugs (ARVs) in the past decade. Much has been achieved through efforts to build and strengthen health systems capable of addressing the complexities of HIV, while at the same time, these efforts have helped to expose the persistent inadequacies of the systems to sustainably deal with chronic conditions like HIV.

The USAID Health Care Improvement Project (HCI) and the USAID Applying Science and Strengthen Systems Project (ASSIST), its follow-on, apply the science of improvement to enable health systems in LMICs to deal with various health challenges, including HIV. HCI’s and ASSIST’s efforts to improve systems of care for HIV have focused largely on health service delivery issues and on working directly with providers at the level of the health facility. The goal of this work has been to achieve efficient, effective, and sustainable systems of providing core HIV care and treatment services and to facilitate the integration of specific service components (e.g., nutrition services) essential to achieving good clinical outcomes. In 2010, with support from PEPFAR, HCI began engaging health system leaders and providers in the deliberate application of the Chronic Care Model to improvement projects. In addition, many improvements implemented by QI teams prior to that could be characterized by CCM principles.

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Applying the Chronic Care Model to health system design in low-resource settings • 1
While there is already a wealth of experience on the application of the CCM in high-income countries to learn from, its use in LMICs, especially at the facility level, has been very limited to date.

The purpose of this report is to discuss: 1) the history, applications, and evidence behind the CCM, 2) the relevance of the CCM for improving health systems and for treating HIV and other chronic illnesses in LMICs, 3) the experiences of HCI and ASSIST in applying CCM principles and lessons learned from these experiences, and 4) how the CCM and its principles could be applied to further benefit improvement efforts in LMICs.

II. THE CHRONIC CARE MODEL: BACKGROUND

The effectiveness of health care is particularly limited by the fact that most health systems are not well designed to address the needs of people with chronic conditions, a problem which has been increasingly recognized in high income countries. In its 2001 landmark report, *Crossing the quality chasm: A new health system for the Twenty-first Century*, the US Institute of Medicine (IOM) brought to light the serious inadequacy of health care delivery systems to meet the chronic health needs of aging populations. They asserted that health care must aim to become more safe, effective, patient-centered, timely, efficient, and equitable. They challenged the country to reinvent its health care delivery system accordingly and laid out the following principles to guide efforts to do so:

- Care is based on continuous healing relationships.
- Care is customized according to patient needs and values.
- The patient is the source of control.
- Knowledge is shared, and information flows freely.
- Decision-making is evidence-based.
- Safety is a system property.
- Transparency is necessary.
- Needs are anticipated.
- Waste is continuously decreased.
- Cooperation among clinicians is a priority.

Renewed attention to health care system deficiencies, such as that brought about by the IOM report, resulted in intensified efforts to examine and improve health service delivery. Over the past two decades, considerable knowledge has emerged from these efforts regarding the benefits and sustainability of various health system design features and improvement interventions, and there is now a sizeable and growing body of literature on health system design for chronic care, some examples of which will be discussed here.

The Chronic Care Model (CCM), based on early evidence in redesigning health systems, has been the most influential and widely disseminated framework for improving care for long-term health conditions. Its core features influenced and are closely aligned with the principles outlined in the IOM report, and the model has been adapted and incorporated into a variety of frameworks used to guide administrators, practitioners, and policymakers, in the United States and other countries, working to strengthen their health systems.

A. History

The Chronic Care Model was developed in the United States in the mid-1990’s by a team led by Edward Wagner at the MacColl Institute for Healthcare Innovation at the Group Health Research Institute in Seattle, Washington. This framework for improving health care delivery systems was devised to optimize the delivery of primary care services and was derived from the team’s own experiences at Group Health Cooperative of Puget Sound and from published evidence on the impact of various practice changes carried out by other chronic disease management programs.
Introduced at a time when the US health system was increasingly shifting to managed care to reduce the costs of health service delivery, Wagner's team argued that to be truly cost-effective, health systems must be designed to improve clinical outcomes first and foremost, even if this requires investments which are initially higher than the cost of interventions that are intended simply to rapidly reduce spending. Wagner's team discovered that health system changes in four areas led to the greatest improvements in patient health outcomes: health information systems, including the use of disease registers; care planning and team-based care delivery; assistance for providers to make better clinical decisions; and education and support for patients to help them make better daily choices involving their health. From these findings they proposed that effective chronic illness care depends on the optimization of four basic, interlinked system components: 1) clinical information systems, 2) decision support, 3) delivery system design, and 4) self-management support.

A Cochrane review of 41 studies published a few years later concluded that four analogous categories of health system interventions resulted in significantly improved processes and intermediate outcomes in diabetes care, further validating the CCM. Experience and reflection by Wagner's team resulted in the incorporation of "health systems" and "community resources" as two additional components of the CCM. These added elements underscore the vital connection between health facilities and the health care organizations supporting them and stress the benefits of linking patients to resources in their communities.

Shortly after the creation of the CCM, the Robert Wood Johnson Foundation supported the launch of the Improving Chronic Illness Care (ICIC) project. This project included several Breakthrough Series Collaboratives, conducted by the Institute for Healthcare Improvement (IHI), in which health facilities applied rapid cycle quality improvement (QI) methods to implement change strategies suggested by the CCM. With a total of 104 health centers focused on improving chronic illness care, this was the first large-scale attempt to systematically apply the CCM in facility-based QI initiatives. The collaboratives included a wide variety of facility-types, each focusing on a single common chronic condition: diabetes, congestive heart failure, asthma, depression, or frailty in the elderly. A wealth of information on how to improve care for chronic illnesses in various clinical settings emerged from this effort, including numerous change concepts and best practices. The success of these early applications of the model led to further dissemination and numerous QI applications of the CCM across the United States and in other high-income countries.

B. Principles

According to the CCM (Figure 1) six interlinked elements of health care delivery systems ideally lead to productive interactions between patients and clinical practice teams, leading to good functional and clinical patient outcomes.

For these interactions to be optimally productive, patients must be informed about their condition and confident enough to be active decision-makers and self-managers. Practice teams must have the expertise, resources, time, and information to be prepared and proactive in the care and support they provide for patients. Early experiences of health facilities in applying the CCM as part of quality improvement initiatives helped define valuable features under each of the model's six components as described below.

At the facility level, a key clinical information system (CIS) improvement was the patient registry which could be used to produce treatment planning reports which also served as visit records. Decision support (DS) tools that were most helpful were those which were embedded into regular patient care documents and records, providing guidelines and reminders to providers during patient visits and visit documentation. Facilitated communication, often electronic, with specialists and other providers, was also particularly supportive of good clinical decision-making.
Figure 1: The Chronic Care Model

The Chronic Care Model

From: http://www.improvingchroniccare.org/?p=The_Chronic_Care_Model&s=2

Delivery system design (DSD) improvements were characterized by planned coordination of care among multiple care team members along with efficient and appropriate delegation of tasks, including patient self-management support and follow-up between visits, among care providers. Planned individual or group visits were often helpful for providing multidisciplinary care.

Traditionally, patient self-management support (SMS) has been equated with patient education. While simple patient education is important for increasing patient knowledge, early evidence revealed that education alone was often insufficient for helping patients to provide good self-care. Interventions designed to empower patients by building confidence and self-management skills proved to be more effective at helping patients to achieve good health outcomes.

At the level of the health care organization (HCO), it was observed that buy-in and support by organization leaders was a strong predictor for success of chronic care improvement projects. Resource allocation and policy development were particularly important means through which organization leaders could facilitate improvement efforts in chronic care. Also found to be beneficial was linkage of patients to community resources (CR), which provided patients with important services that were not available in or through the health facility. Linkages to other health facilities and organizations in the community were also important, especially to ensure continuity of care.

C. Evidence

In 1999 a research team from RAND Corporation and the University of California at Berkeley was commissioned to carry out a four-year, detailed evaluation of the early work on improving chronic care using the CCM. Evaluations were conducted across 51 sites which had participated in four improvement collaboratives involving almost 4,000 patients with diabetes, congestive health failure, asthma, and depression.

The research team developed a framework for assessing the “fidelity” (alignment of changes with model elements) and “intensity” (quantity and depth of interventions) of CCM implementation. Using this framework, 42 sites, which had participated in either an IHI-ICIC collaborative or the Washington State Diabetes Collaborative II, were evaluated. Fidelity to the model was high, with 98% of sites making changes in at least five of the six CCM elements and 81% making changes in all six elements, while
intensity of interventions tended to be modest. The framework divided the six CCM elements into 23 sub-categories (Table 1). The researcher found that interventions were made by sites in an average of 15 of these sub-categories.12

### Table 1: Subcategories of CCM-based changes

<table>
<thead>
<tr>
<th>Chronic Care Model Elements and Sub-Categories</th>
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<tbody>
<tr>
<td><strong>Clinical Information System (CIS)</strong></td>
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<tr>
<td><strong>Decision Support (DS)</strong></td>
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<tr>
<td><strong>Delivery System Design (DSD)</strong></td>
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<tr>
<td><strong>Self-management Support (SMS)</strong></td>
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<td><strong>Community Resources (CR)</strong></td>
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<td><strong>Health Care Organization (HCO)</strong></td>
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<td>Patient registry</td>
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<tr>
<td>Guideline institutionalization and prompts</td>
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<td>Care management roles</td>
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<tr>
<td>Patient education</td>
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<tr>
<td>For patients</td>
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<tr>
<td>Leadership support</td>
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<tr>
<td>Use of information for care management</td>
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<tr>
<td>Provider education</td>
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<tr>
<td>Team practice</td>
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<td>Psychosocial support</td>
</tr>
<tr>
<td>For community</td>
</tr>
<tr>
<td>Provider participation</td>
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<tr>
<td>Feedback on performance data</td>
</tr>
<tr>
<td>Expert consultation support</td>
</tr>
<tr>
<td>Care delivery/coordination</td>
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<tr>
<td>Self-management assessment</td>
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<tr>
<td>Coherent system improvement and spread</td>
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<tr>
<td>Pro-active follow-up</td>
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<tr>
<td>SM resources and tools</td>
</tr>
<tr>
<td>Planned visit</td>
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<tr>
<td>Collaborative decision-making with patients</td>
</tr>
<tr>
<td>Visit system changes</td>
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<tr>
<td>Guidelines shared with patients</td>
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The site teams had used the Assessment of Chronic Illness Care tool,13 developed by Wagner’s team, for self-assessment before and after their QI activities and typically focused on addressing areas of self-identified weakness. Overall, the greatest emphasis was placed on CIS while CR received the least attention. Organizations made an average of 48 changes in 5.8 out of the 6 CCM areas. One year after participation in a collaborative, 82% of participating sites had sustained improvements, and 79% of sites had spread change to other places and/or diseases.

The same group performed a meta-analysis covering 112 studies on chronic care improvement efforts which included one or more of the types of changes described by the CCM.14 They found that interventions to improve self-management support (SMS) were most common with DSD and DS interventions being second and third most common, respectively. The authors reported that while the data were too complex for detailed conclusions, improvements in some elements of the CCM seemed to yield benefits in terms of processes, clinical outcomes, and patient quality of life. They speculated that SMS and DSD interventions are most beneficial while improvements in other CCM elements provide important infrastructure for chronic care service delivery.

In 1998, the US Health Research and Services Administration (HRSA) launched a quality improvement initiative which specifically targeted chronic conditions care in underserved populations served by community health centers. This initiative, called the Health Disparities Collaboratives, ultimately reached...
more than 640 health centers. The Chronic Care Model was used to identify target areas and guide improvement interventions. A retrospective study conducted on 44 of the participating health centers revealed significant process improvements for diabetes and asthma compared to controls. There were no significant improvements, however, in processes for addressing hypertension. Neither were there significant improvements in intermediate clinical outcome indicators for any of the three chronic conditions of interest.

Experience and evidence on applying the CCM continued to accumulate, and in 2009, Wagner's group published a review on the effectiveness of applying multiple components of the CCM through QI initiatives in the US, Europe, Canada, and Australia. The team learned that through application of CCM principles, care improved in several areas as evidenced by the following examples:

- Patients with congestive heart failure were more knowledgeable, more adherent, and spent 35% fewer days in the hospital;
- Asthma and diabetes patients were more likely to exhibit improved self-management practices, receive appropriate therapy, and report improved quality of life; and
- Diabetes patients exhibited reduced risk for cardiovascular events.

Despite these successes, there were also instances where no process and/or clinical outcome improvements were evident. Short follow-up periods, low participation rates, and poor study designs were considered to be possible contributors to these negative results. Studies on the HRSA-sponsored Health Disparities Collaboratives, targeting underserved populations, revealed significant process improvements at the end of collaborative participation. However, no significant clinical outcome improvements were apparent until two years following the end of the collaborative, suggesting that although process improvements can occur quickly through CCM use, it takes much longer for these to quantifiably impact clinical outcome measures.

Viewing the CCM as a model designed to guide an integrated approach to improving chronic care, the review considered whether improvements in all or most of the six elements of chronic care are necessary to improve processes and outcomes. Some evidence suggested that it is more effective to address multiple CCM components, but studies were limited by the analytical challenges of disentangling complex, multi-component interventions.

Another concern of the review team was the cost-effectiveness of CCM-based interventions. Though the evidence base on cost-effectiveness was very limited, one study estimated that the per-patient cost of implementing the CCM was USD $6-$22, a figure considered to be highly cost-effective in terms of quality-adjusted life years (QALYs).

D. Adaptations and Applications

Encouraged by its early success and rapid spread, health system improvement leaders have broadened the applicability of the CCM by adapting it to various contexts and by integrating it into other health system improvement concepts. For example, a team from Vancouver Island Health Authority in Canada proposed that in order to more fully address the burden of chronic disease on population health, the CCM should reach beyond its emphasis on improving clinical services for people with chronic disease. They believed that the model should be broadened to address clinical and community-based health promotion and preventive services as well, in order to promote reductions in the total chronic disease burden. The expanded model which they proposed was informed by the social determinants of health and elaborated upon the community component of the original CCM, in order to guide actions to address health determinants. In this expanded chronic care model, the four core elements straddle the health system and the community, and three elements are added to the community portion of the model (Figure 2).
Productive interactions between an activated community and prepared proactive community partners complement interactions between patients and practice teams to achieve not only improved clinical outcomes but also improved population health. The “Expanded Chronic Care Model” is used across Canada and has been incorporated into a chronic disease prevention and management tool developed by the Public Health Agency of Canada.18

In 2003, the World Health Organization reformulated the Chronic Care Model in an effort to be more relevant in a variety of global settings and especially to guide policy development in low and middle income countries.19 The WHO version, called Innovative Care for Chronic Conditions (ICCC) and shown in Figure 3, is based on the CCM but provides detail on important health care policy components. It also emphasizes and provides some detail on the role of community, stressing integration and coordination across all levels of the health system.

The ICCC has been endorsed by many Ministries of Health and has informed the development of strategic policy frameworks aimed at adapting health systems to accommodate the long-term care and treatment of people living with chronic conditions. In countries with a high prevalence of HIV, the model has had a considerable influence on strengthening health systems to provide for the long-term needs of people receiving HIV care and treatment.

The CCM has been adapted and integrated into health care redesign concepts by many other institutions across the globe.20,21,22 A notable example in which the CCM was integrated into a much broader model is the patient-centered medical home (PCMH), a notion which began growing into a major health system re-design movement in the US starting in 2006.23 In its present form, the PCMH incorporates the CCM for practice redesign and is built on seven core features: personal physician, physician-directed medical practice, whole person orientation, integrated care, quality and safety, enhanced access, and payment reform.24 The PCMH has been extensively endorsed in the US medical community and is being widely disseminated in response to rising health care costs and recognition that comprehensive primary care is critical to enhancing health system performance.
The CCM was originally designed to guide improvement of primary care delivery systems, and most applications of the model have targeted primary care. The broad applicability of its principles has been recognized beyond the primary care setting, however. For example, a team from Australia proposed applying the model in the acute setting for elderly people hospitalized for chronic illnesses. Influenced by the WHO version of the CCM and desiring to improve patient-centeredness and continuity of care, they made an interesting case that CCM principles employed in the hospital setting could help prevent readmissions as well as improve patient health status and quality of life.

E. The CCM and HIV

With the introduction of antiretroviral therapy (ART) and the resulting transformation of HIV into a long-term, chronic condition, there has been considerable movement toward employing the CCM as well as the patient-centered medical home to improve HIV care and treatment programs in high-income countries. In a recent prospective interventional cohort study at two community health centers in urban British Columbia Canada, implementation of all model components resulted in significant improvements in process and clinical outcome quality measures including: pneumococcal vaccination, syphilis screening, tuberculosis (TB) screening, ART uptake, and viral load suppression.

The relevance of the CCM to HIV care is so apparent that in some instances improvement efforts in HIV programs which have not intentionally used the CCM, are being retrospectively examined for the effectiveness of specific interventions which can be classified under CCM components. For example, a recent review examined 16 reports on interventions to improve HIV care and treatment which the reviewers categorized as either DS or CIS. Most of these were from the US or Europe, but three were from sub-Saharan Africa. The team concluded that interventions pertaining to decision support...
and clinical information systems seem to have yielded improvements, having a greater impact on process measures than on outcome measures. The heterogeneity of the interventions and settings in the included reports, however, limited their analysis.

In many LMICs, especially in sub-Saharan Africa, HIV is the first chronic condition to receive substantial enough funding levels for care and treatment to reach significant portions of the disease-afflicted population. Consequently, in many countries where Ministries of Health have endorsed the WHO version of the CCM, HIV program development has been the principal application of the model. In the context of the emergency response to the HIV epidemic driven by funding from PEPFAR and the Global Fund, most of the focus on expanding HIV care in LMICs has been on putting in place the resources needed to provide HIV care and treatment including: physical infrastructure, laboratory development, recruitment and training of health workers, and the introduction of new drugs and technologies. In the context of the emergency response to the HIV epidemic driven by funding from PEPFAR and the Global Fund, most of the focus on expanding HIV care in LMICs has been on putting in place the resources needed to provide HIV care and treatment including: physical infrastructure, laboratory development, recruitment and training of health workers, and the introduction of new drugs and technologies. Meanwhile, facility-level system design and improvement applications of the model have been minimal in these settings.

In high-income countries, substantial resources have been invested into addressing the psychosocial complexity of living with HIV along with the particularly crucial importance of strict adherence to HIV treatment regimens. Accordingly, good HIV “self-management” is widely recognized as the key to achieving long-term treatment success. In response to the transition of HIV from a terminal illness to a long-term chronic condition, a pioneering and innovative program in patient self-management support was launched in the late 1990’s by the California VA Health System. This “Positive Self-Management Program” for HIV has spread to other health systems in California and elsewhere and has been used as the basis of published texts written to help patients with HIV and other chronic conditions self-manage. Based on experience with this program, self-management support has been described as a collaborative effort between patients, providers, and systems of care. When successful, SMS helps patients develop the knowledge, confidence, and behavioral skills to cope with their condition and successfully manage the day-to-day challenges of living with the disease.

F. Self-management Support in Chronic Care

It is in fact becoming widely acknowledged that most decisions about chronic illness care are not made by providers during patient clinical encounters. Rather, these are self-management decisions made on a daily basis by patients themselves. Consequently, the critical role of SMS in chronic illness care has, as in the HIV example above, received considerable attention independently of more comprehensive models for chronic care service design, and there is mounting evidence of the effectiveness of SMS programs. For example, in one of the earliest randomized controlled trials examining the effectiveness of a self-management support program in the context of more than one chronic condition, patients with heart disease, lung disease, stroke, or arthritis participated in a six-month SMS program designed to improve both knowledge and behaviors pertinent to their health. Through self-administered questionnaires, patients overwhelmingly reported improved health behaviors and health status as well as decreased hospitalizations, compared to controls. In 2011, the UK Health Foundation published what is likely the most comprehensive review to date on the topic of self-management support. The review covered 550 studies from around the world, including systematic reviews, randomized controlled trials, and observational studies covering SMS interventions for a wide variety of chronic conditions. A continuum of interventions was examined, ranging from passive information provision (e.g., pamphlet distribution) to active support aimed at changing behaviors along with comprehensive programs which included a variety of different means of support. According to the evidence, simple information provision (especially using passive means like pamphlet distribution) is not typically an effective way to help patients achieve sustained behavior change or improved clinical outcomes. The types of SMS interventions which the evidence generally did reveal to be effective include:
• Engaging patients in decision-making
• Teaching problem solving skills
• Partnering with patients in developing care plans
• Setting goals and following up on them
• Promoting healthy lifestyles in the context of patients’ conditions
• Teaching patients how to monitor their symptoms and take appropriate actions based on those symptoms
• Helping people to recognize and address the social, emotional, and physical issues related to their conditions
• Creating sharing opportunities among patients with similar conditions

It also appeared that certain interventions were more effective for some chronic conditions than for others, suggesting that SMS programs should be somewhat tailored to disease characteristics. Furthermore, many studies revealed that SMS worked best when implemented along with other interventions such as decision aids, information technology, and community partnerships, strengthening the argument that the elements of the CCM are interlinked and that the other elements (e.g., decision support, clinical information system, community resources) provide important infrastructure for maximizing the effectiveness of SMS. The article highlighted emerging evidence that strategies created and often implemented by service providers in partnership with patients are particularly effective. The review emphasized that in fact, the best self-management support appears to involve the building of effective relationships between providers and patients. Finally, the author concluded that SMS should be conceptually defined in two ways: 1) a portfolio of techniques and tools to help patients make healthy decisions, and 2) a transformation of the patient-provider relationship into a collaborative partnership.

This emphasis on helping providers partner with patients to help them make their own health decisions is consistent with the concept of “patient-centered care”, a term actually coined in 1988 by the Picker Institute. This US-based organization with European branches has been an influential leader in examining patient health care experiences and perspectives and promoting safety and quality in health care. Based on years of research regarding patients’ perspectives on health care, they delineated eight characteristics of “patient-centered” care: 1) respect for patients values, preferences, and expressed needs; 2) coordination and integration of care; 3) information, communication, and education; 4) physical comfort; 5) emotional support and alleviation of fear and anxiety; 6) involvement and support of family and friends; 7) continuity and transition and 8) access to care.

III. DESIGNING A SYSTEM FOR BETTER CHRONIC CARE IN AFRICA

As part of its program to improve the quality of HIV care in high-prevalence countries in Sub-Saharan Africa, the USAID Health Care Improvement Project proposed to USAID and PEPFAR that the project convene a design meeting bring together experts and stakeholders to explore how to apply the CCM to improve the chronic care of HIV in Africa. Uganda has been a leader in HIV care among African nations, and due to keen interest by the Ministry of Health, the Chronic Care Design Meeting was convened in Kampala in May 2010. Officials from Uganda’s MOH, USAID, and HCI and local and international experts in HIV and chronic care participated. The some 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 the second day of the Design Meeting, participants broke into group to visit a hospital in Entebbe and health centers in Luwero and Kangulumira, to gain a firsthand understanding of how chronic conditions care was currently are being handled in facilities and the systems that surround that care. By viewing some of the successes in these Ugandan sites, such as utilizing expert clients, village health
teams, and improved 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.

Using the WHO’s CCM as a point of reference, 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 made by the participants in the design meeting 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) attended the conference, heard 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, 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 would 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 would occur through a demonstration project to learn how to implement the CCM in one district in Uganda, Buikwe. Based on the promising conclusions of the Chronic Care Design Meetings, PEPFAR agreed to support the Chronic Care Demonstration Collaborative in Buikwe and later support implementation of CCM components in Tanzania.

IV. HCI’S EXPERIENCE APPLYING CHRONIC CARE MODEL PRINCIPLES TO IMPROVE HIV CARE AND TREATMENT IN LOW-RESOURCE SETTING

Programs employing improvement science to enhance the development and adaptation of health care in LMICs have met with considerable success, underscoring the fact that health systems which are limited by resource constraints are further weakened by deficiencies in the service delivery processes to which improvement interventions are targeted. HCI has applied improvement science, rooted in the Model for Improvement (Figure 4), to systems providing long term care and treatment for people with HIV on four continents.

This section will examine efforts supported by HCI in East Africa and discuss lessons learned from them in the context of the CCM. Improvement efforts for chronic care of HIV supported by HCI can be categorized as: 1) interventions for integrating essential primary care services, such as nutrition and palliative care, for HIV patients into existing programs, and 2) interventions for improving core care and treatment services, including ART and basic prevention and treatment of opportunistic infections.
A. Integration of Essential Primary Care Services

Family planning, TB care, nutrition, and palliative care are among the essential primary care services for people with HIV which HCI worked to integrate into HIV care and treatment programs. All of these activities have incorporated interventions which are in accordance with CCM principles. This report will discuss efforts to improve the integration of nutrition and palliative care with HIV services in order to illustrate this alignment of service integration with CCM principles.

From 2008-2011 the USAID NuLife project in Uganda worked with the Uganda Ministry of Health (MOH) to establish comprehensive nutrition support for patients of all ages at 54 HIV care and treatment sites throughout the country. This involved the development and updating of policies, guidelines, and training materials as well as the provision of training and procurement of commodities. NuLife enlisted HCI to provide improvement support in order to ensure that delivery systems consistently provided high quality services. Although the CCM was not deliberately employed in the approach to improvement, Uganda’s MOH, which was actively engaged in the project, had adopted the WHO CCM to guide the country’s HIV programming policies with which it considered NuLife/HCI objectives and approaches to be closely aligned. NuLife engaged leaders at all levels of the health system, a measure which is consistent with the health care organization principle of the CCM. Furthermore, in order to integrate comprehensive high quality nutrition services, interventions were implemented which were consistent with all other CCM principles.

To aid in training health workers and to help them continuously identify areas in need of improvement, nutrition care was divided into seven steps: assessment, categorization, counseling, food-by-prescription, follow-up, community links, and patient education. Sites collected data and applied improvement methods to optimize service delivery at each step, achieving significant improvements for all aspects of nutrition service delivery. Key interventions which were in-keeping with CCM principles included:

- Clinical information systems: Most sites added a nutrition assessment column to the HIV clinic attendance register; and NuLife worked with the Uganda MOH to add key nutrition information to its updated HIV care and treatment card.
- Decision support: Training on nutrition was provided to health workers along with ongoing coaching; and health workers used nutrition education cards developed by NuLife and approved by the MOH to assist in providing nutrition education to patients.
• Delivery system design: Challenged by human resource constraints, group nutrition counseling was often preferred over individual counseling; volunteers, including expert patients, were enlisted to carry out many key tasks, including counseling and nutrition assessment.

• Self-management support: Nutrition education and counseling for patients were provided through group and individual sessions; and nutrition cards (as mentioned under decision support) were used in these sessions.

• Community resources: Several measures were carried out to involve the community, including: facility based volunteers working directly with community health workers (CHWs) to address patient concerns; CHWs participating in facility QI meetings; and CHWs being enlisted to refer patients for nutrition services using referral forms developed for this purpose.

In 2011, many of the improvements from the NuLife-HCI activity were spread to a small-scale (eight sites) demonstration collaborative in Kenya. This initiative focused on improving nutrition care at HIV treatment facilities supported by a food-by-prescription program and yielded delivery system changes and improved quality measures similar to those in the NuLife project.

A 14-month collaborative improvement project was launched in 2010 in which HCI worked with the Uganda MOH to integrate palliative care, focusing on pain management, at 13 facilities providing HIV care and treatment services in two rural districts. As with NuLife and the Kenya nutrition collaborative, health system leaders at all levels were engaged to provide appropriate support for the initiative. Though there was no deliberate attempt to apply the CCM, the involvement of health system leadership was again consistent with its HCO principle. In addition, most other key interventions were in harmony with the CCM, for example:

• Clinical information system: All sites adopted the introduction of a column on the HIV care and treatment card to record pain assessment; palliative care registers and special forms were introduced to assess and follow patients with complex pain management needs; morphine stock cards were introduced to monitor morphine supplies; and morphine registers were maintained to facilitate morphine prescribing.

• Decision support: Training and coaching were provided to health workers, community volunteers, and morphine prescribers; pain assessment and management job aids were posted on facility walls; a standard 1 – 5 pain scale was adopted to consistently score pain; and an inter-facility referral system was established for management of patients with severe pain.

• Delivery system design: ART clinics were re-scheduled to days which were typically less busy for provision of other clinical services in order to provide more time for patient care, including palliative care; and expert patients were assigned to the triage station to identify patients needing pain management.

• Self-management support: Patients were counseled on self-management of pain, including use of pain medicines; and family members were enlisted to assist with care.

• Community resources: Community volunteers were engaged to sensitize their communities about the availability of treatment for pain and to identify and refer patients; volunteers were included in facility QI team meetings and also held their own team meetings; and referral notes were developed to facilitate referrals by community volunteers.

Several important lessons have been learned from HCI’s efforts to enhance the integration of essential primary care services into HIV treatment programs. These lessons are relevant to the application of improvement science, including CCM implementation, in LMICs in general:

• Nutritional support, palliative care, management of co-morbidities, and other primary care services are critical in achieving the basic goals of chronic care (i.e., prolong life and enhance quality of life).
• Engagement of local health officials is key to garnering interest and motivation among health workers and important for sustaining gains.
• It is helpful to break services down into key steps or processes and have teams work at analyzing and improving each step individually.
• Expert patients offer volunteer or inexpensive labor, and can play a crucial role in driving process improvements forward and in achieving sustainability of key interventions.
• Health worker training alone is insufficient to achieve and sustain minimal service delivery standards; it must be complemented by supportive supervision and continuous quality improvement.
• Community engagement enhances continuity of care and supports patient self-management.
• A reliable supply chain must be established and sustained for improvement efforts to be credible and for health workers to be motivated to champion the introduction of services and the strengthening of service delivery practices.

B. Improving Core HIV/AIDS Care and Treatment Services

HCI’s approach to improvement of core HIV/AIDS care and treatment services has been guided by the notion that HIV/AIDS programs should fundamentally aim to maximize: 1) coverage of people eligible for the services, 2) retention of patients in HIV/AIDS treatment programs, and 3) clinical outcomes for those receiving care and treatment. To assist in the ongoing pursuit of these aims, HCI began working with facility-level teams in Uganda since 2010 to actively employ the CCM to quality improvement efforts in HIV/AIDS programs. During this time, a parallel effort focusing mainly on self-management support has been underway in Tanzania.

In Uganda, where the CCM has been applied comprehensively, the launch of CCM activities was preceded by a Chronic Care design meeting held in May of 2010, where the Ugandan MOH affirmed its commitment to health system re-design to improve care for HIV and other chronic illnesses. The meeting also raised awareness among participants from other countries about the need for and feasibility of improving health systems to better meet the needs of people with chronic diseases. HCI subsequently worked with the Ugandan MOH to launch a demonstration collaborative improvement initiative where participants used the CCM to examine and improve their health care delivery systems. Buikwe District was chosen for the intervention, and officials at the district level of the health system were engaged to participate in and ultimately lead this effort. The CCM was introduced to providers from the 15 participating facilities during a technical training on care for common chronic illnesses. The providers were encouraged to examine their systems of care through the lens of the CCM and to consider changes that could improve aspects of care categorized under each CCM component. The larger and older HIV treatment programs concluded that their systems were relatively strong, in the context of available resources, in the areas of CIS, DS, and DSD. For example, these sites had long established and mastered the use of longitudinal registers and HIV treatment cards according to the CIS system developed by the MOH. They therefore focused on improving SMS, the area in which they felt their care systems to be weakest. QI teams at smaller, newer sites concluded that improvement was needed in all areas. For example, these teams worked to improve CIS through introduction of longitudinal records and registries, enhance DS through training as well as guideline procurement and job aids, and achieve more effective and efficient DSD through the introduction of triage processes and task-shifting. Improvements in SMS at all sites included enhanced counseling and other measures to help patients establish goals and make progress toward overcoming challenges to achieving those goals. Expert patient volunteers were recruited to help achieve many of the changes, especially in the areas of DSD and SMS.

A complete list of interventions for each element of the CCM is described in the Appendix. Data on coverage, retention, and clinical outcome gaps at the five sites in Buikwe that provided comprehensive
ART care revealed a significant increase in coverage of persons eligible for ART, with improved patient retention and clinical wellness over the course of the collaborative (Figure 5). Furthermore, achievements in coverage, retention, and wellness were not only sustained but also enhanced over a period of nine months following the end of the intervention.

**Figure 5: Coverage, retention, and clinical outcome gap analysis showing improvement at five sites implementing the CCM in Buikwe District, Uganda**

Improvement teams experimented with several different self-management support interventions, some of which were ultimately adopted. Notably, a tool was developed for goal-setting and action planning which counselors, providers, and expert patients used to assist patients in overcoming challenges to providing good self-care. Furthermore, SMS groups were formed for patients with similar challenges to share their experiences and provide mutual support. At eight sites implementing the tool along with SMS groups, patients increasingly set goals to overcome challenges and made progress toward meeting those goals (Figure 6).

In Tanzania, the CCM was introduced at 14 sites in two districts in the region of Morogoro. QI teams and health system officials examined the CCM and elected to focus on SMS as the weakest and most critical component of their HIV care delivery systems. Due to human resource constraints, facilities decided to recruit expert patients, called “peer mentors,” to help enhance the quality of SMS provided to patients. This was an entirely new cadre of health worker in Morogoro Region, and considerable reflection and effort went into their selection and introduction into health facility operations. Health workers and expert patients received training in SMS and decided to provide enhanced group education along with individual counseling to help patients identify challenges, set goals, and work toward achieving those goals. Over time, there were increases in goal setting and action planning, adherence, self-reported confidence to self-manage, appoint-keeping, and clinical outcomes. Although the teams were focused on SMS, it was observed that changes in other components of the CCM were also put into place in order to facilitate (or as a result of) SMS interventions (Table 2). For example, in addition to
their role in SMS, expert patients assisted in making delivery system design more efficient by taking over simple clinic tasks previously performed by providers. Also, as members of the community, in which many of them also served as home-based care workers and community organization leaders, expert patients greatly assisted in enhancing community linkages and patient access to community resources.

Figure 6: Patients identifying challenges, setting goals, and making progress toward achieving those goals through SMS at eight sites in Buikwe District, Uganda

![Number of patients with challenges and number setting goals at 8 sites, May 2011-Aug 2012](image)

Table 2: Changes to the health care delivery system according to CCM components at sites implementing SMS in Morogoro Region, Tanzania

<table>
<thead>
<tr>
<th>CCM component</th>
<th>Input</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Patient self-management support</strong></td>
<td>Principal intervention described</td>
</tr>
<tr>
<td>Delivery system design</td>
<td>55 expert patients assist with various tasks, in addition to patient self-management support</td>
</tr>
<tr>
<td>Decision support</td>
<td>Expert patients and health workers provided with job aids and guidelines on self-management support</td>
</tr>
<tr>
<td>Community resources</td>
<td>Community-based organizations/community leaders engaged</td>
</tr>
<tr>
<td>Clinical information system</td>
<td>Expert patient self-management registers introduced; CIS use strengthened; data base established</td>
</tr>
<tr>
<td>Health care organization</td>
<td>Patient SMS being integrated as a component of updated home-based care system</td>
</tr>
</tbody>
</table>
In Uganda, where the model was applied comprehensively, the CCM was a useful way for QI teams to frame the features of their HIV care and treatment programs in order to systematically examine which features were in need of improvement. For participating programs that were already well established at the start of the collaborative, the CCM served to help participants understand how existing components of their service delivery systems fit together to make chronic HIV care possible. This facilitated the identification of remaining gaps in their care systems. For HIV treatment programs which were in the early stages of development or which were just being launched, the model served as a blueprint for the establishment of service delivery systems by highlighting what health system design features were necessary for adapting their services, which previously addressed only acute health needs, to the long-term needs of HIV patients.

It is particularly interesting that in Uganda, the efforts to improve HIV care around the CCM brought to light for health workers the fact that health system components in place to facilitate HIV care and treatment, should also be in place for other chronic illnesses, such as hypertension and diabetes. Even the larger facilities acknowledged that these chronic non-communicable diseases were generally being treated as acute conditions in their systems of care, leading to very poor outcomes for patients. In a “spillover effect,” most QI teams consequently introduced features such as longitudinal records, patient education, and designated clinic days to diabetes and hypertension care.

While it was recognized that the CCM is a set of interlinked elements that form a foundation for good chronic care and that efforts to establish or improve each of these components strengthens the overall health system, participants from established programs identified SMS as the area where their largest gaps existed. This is likely due to the fact that SMS must address the complex psychosocial needs of patients and is a multifaceted service that can be particularly challenging to optimize. It is also the component of chronic care that is likely most critical to improving patient outcomes. To be able to make good daily health choices, patients with chronic conditions must be empowered with the knowledge, skills, and self-confidence to effectively negotiate the ongoing hurdles of living with these conditions and the decisions involved in providing good self-care. Where teams chose to focus mainly on SMS, it was essential to strengthen other interlinked components of the CCM in order to sustain improvements. This is consistent with the suggestion of the RAND research team that other CCM components provide infrastructure important for sustaining the implementation of complex SMS interventions.14

In light of the severe health worker shortage in Sub-Saharan Africa, it is important to consider the impact of CCM-guided QI efforts on health worker satisfaction and performance. Feedback from health workers on using the CCM has been mostly positive. Health workers have particularly appreciated the redesign of the delivery system to streamline patient flow and appropriately assign clinic tasks to lower ranking health workers, including expert patients. These changes have allowed providers more time to concentrate on clinical care. Interventions to improve SMS had the potential to add more workload to overstretched staff. However, using careful redesign of the delivery system including careful allocation of tasks, facilities in the Uganda collaborative recuperated the time needed to improve self-management support by making other processes more efficient. In Tanzania, expert patients were trained to provide much of the additional patient support needed to improve patient self-management. In addition, they took on a variety of other clinic tasks, saving considerable time in the workdays of clinicians. Through strategic assignment of tasks in both countries, expert patients played key roles in enhancing self-management support and in decreasing the burden of routine clinic tasks on clinicians, adding to mounting evidence that people with HIV have much to offer in providing care for one another.
V. IMPLICATIONS FOR FUTURE HEALTH CARE IMPROVEMENT IN LMICS

A. Application and Adaptation of the CCM

Results from HCI chronic care improvement efforts are highly encouraging. This is with respect both to the use of the CCM to guide improvement for core HIV care and treatment services and to the integration of primary care services for HIV patients. These experiences are consistent with much of the research on the CCM in high-income countries, suggesting that although fidelity and intensity of application of general CCM principles is beneficial, specific interventions developed through use of the model may be inappropriate or unhelpful in certain contexts. After years of experience with the CCM in high-income countries, Wagner’s team concluded that it is, “not a discrete, immediately replicable intervention; it is a framework within which care delivery organizations translate general ideas for change into specific, often locally distinctive applications.”16 This description would seem particularly relevant to the application of the model in LMICs where local conditions can vary markedly. Due to inconsistent availability of resources and varying capabilities in different types of facilities, QI teams may elect to focus their efforts only on certain components of the model. In fact, some evidence from high-income countries suggests that delivery system design and self-management support interventions have the greatest impact on processes and outcomes.44, 45 As with the SMS intervention in Tanzania, teams may find that by focusing on improvement in one key area, they also strengthen other aspects of their service delivery systems.

Since the development of the original CCM, many tailored versions of the model have been created as described above. The most influential of these tailored versions is likely the ICCC developed by the WHO. Although it has not been researched nearly as extensively as the CCM, ICCC has been particularly helpful in guiding the development of national health policies on adapting health systems to chronic conditions care.46 Due to its emphasis on issues which are particularly critical to strengthening health systems in LMICs such as policy, finance, human resources, and community, the relevance of the ICCC in the context of LMICs cannot be overstated. At the facility level, however, quality improvement teams in Uganda found the original version of the model to be more straightforward to use in terms of forming a common understanding of the gaps in their service delivery systems and formulating interventions to close those gaps. In such settings, one approach would be to use both models, with the ICCC serving as a roadmap to guide all levels of the health system and the original CCM used to drive facility-based improvement interventions. Alternatively, features of both models may be used along with local considerations to formulate more finely tailored improvement frameworks.

B. Integration

Integration is a feature of good chronic care systems that is included in the original CCM and developed further in the ICCC to address the particularly fragmented care provided by health systems in many LMICs. The term “integration” may refer to that which occurs between: health care and economic development; levels of the health system; levels of patient care; social and health services; and core services and essential primary care services. All of these are important in meeting the long-term needs of people with chronic illnesses.

Though established models of chronic care do not address all types of integration, the utility of emerging care models tailored for health systems in LMICs could be enhanced considerably by incorporating the integration of essential primary care services. This is because people with HIV/AIDS and other chronic illnesses can have multiple co-morbidities and symptoms. A comprehensive set of health services should be available to them over the course of their illness in order to optimally prolong life and reduce suffering. One group of researchers focusing on HIV in Sub-Saharan Africa recently recommended that a basic package of HIV care and treatment should include: identification of people needing care;
counseling on living with HIV; management of HIV-related infections; ART; sexual and reproductive health; management of non-infectious complications of HIV; mental health care and psychosocial support; nutritional support; and laboratory support. In addition, many would argue that no system of caring for a long-term, life-threatening illness like HIV would be complete without the inclusion of palliative care, the service area which specifically emphasizes mitigation of suffering to enhance quality of life. 

With its intrinsic emphasis on communication, patient-centeredness, and family involvement, palliative care serves to enlighten health workers and families about the importance of including these features in all aspects of care.

Initiatives aimed at improving essential primary care services, such as the efforts to integrate nutrition and palliative care described above, demonstrate the effectiveness of improvement science in enhancing this type of integration. It is noteworthy that although the CCM was not intentionally used in these interventions, most changes introduced by teams working on nutrition and palliative care could be classified according to the CCM. It is reasonable to infer that future efforts to integrate essential primary care services could be facilitated by using the CCM to design a set of harmonized interventions aimed at achieving comprehensive facility-level improvement.

C. Health Workforce

Throughout the introduction and implementation of chronic care model principles in the activities described in Tanzania and Uganda, health care workers were informally polled and primarily expressed enthusiasm about the interventions. While QI initiatives by their nature engage health care providers in implementing improvement activities, interventions should also continuously monitor the impact of improvements on health worker job satisfaction and retention. Group Health Collaborative or Puget Sound, where the CCM was first developed, frequently works to develop innovative solutions to health system problems. In applying the CCM in 2002, they made changes to their system aiming to increase patient access to physicians. This forced physicians to work harder and faster, decreasing job satisfaction and quality of life. Physician retention declined, and Group Health was forced to reinvent its system, leading ultimately to the invention of the modern PCMH. This lesson from a high-resource setting is even more relevant in low-resource settings where the health workforce is typically overstretched, often under-compensated, and generally too fragile to jeopardize by introducing changes that may place unreasonable demands on them. Similar considerations are important for building up and supporting CHWs. Whenever services are introduced or enhanced, it is important that measures are taken to preserve and/or strengthen the existing workforce. Such measures include task-shifting and the introduction of lay workers, especially expert patients, a low-cost and often highly motivated cadre of workers who can help other patients by sharing inside expertise on living with HIV that can only come from having the disease. As members of the community who work in health facilities, expert patients can also serve as critical linkages between the formal health system and the community, a notion depicted in Figure 7 by a team examining chronic care for diabetes in rural Alabama, US.

D. Informing Care Delivery Systems: Chronic Illness Care and Beyond

The scale-up of HIV treatment programs in LMICs has been called the “largest public health experiment ever performed” because it unfolded with scant evidence on programmatic effectiveness to guide implementation until research performed concomitantly could inform evolving care systems. In fact, the rollout of HIV care and treatment provided the first major opportunity for many countries to obtain sufficient targeted resources to address a widespread chronic illness on a grand scale. After more than a decade of spreading HIV care and treatment in LMICs, there is now a wealth of experience to guide future scale-up of care for neglected chronic illnesses. In the HCI-supported CCM intervention in Uganda, QI teams using the CCM to guide their activities for improving HIV care and treatment quickly realized the obvious applicability of the CCM to other chronic illnesses. In a prime example of leveraging HIV/AIDS lessons for strengthening care of other diseases, providers spread care system features in...
Figure 7: Role of peer advisors (expert patients) in diabetes management in the context of the chronic care model

Abbreviations: A1c = hemoglobin A1c; BP = blood pressure; LDL = low-density lipoprotein cholesterol

place for HIV to the delivery of diabetes and hypertension care and treatment. This shift from an acute approach to a chronic approach to treating these non-communicable diseases (NCDs) very rapidly resulted in dramatic improvements in intermediate outcomes. As the global burden of disease moves increasingly toward NCDs, this experience, and reports from other programs that have successfully addressed NCDs in association with HIV care and treatment, should serve as heralds of what may be quickly achieved once serious investments are made in scaling up NCD prevention, care, and treatment. In a recent working paper on NCDs and road traffic injuries, the World Bank made and described the following recommendations on what must be done to alleviate the burden of these growing challenges: 53

- Ensure synergies between MDGs and NCDs to maximize resource envelopes
- Put primary focus on prevention and population based actions
- Promote treatment as prevention and effective care
- Adapt and strengthen health systems
- Revisit governance for health

The similarity of these messages to much of the guidance that emerged around HIV care and treatment roll-out further substantiates the notion that efforts to enhance care and treatment of NCDs in low resource settings can be accelerated by leveraging knowledge and practices from successful systems for HIV service delivery. The appropriateness of the CCM in this context is further substantiated by the fact that almost all of the evidence which has accumulated around the use of the CCM in high-income countries has been based on experiences with its application in caring for people with NCDs.
Models and best practices from high-income countries have provided much guidance to global health leaders, programmers, and practitioners in introducing modern medical technologies to LMICs. The WHO defined six building blocks of health system strengthening in order to steer the spread of these technologies via supportive health service delivery systems. These building blocks must be approached with considerable sensitivity to local conditions and tailored accordingly. In a recent health policy article, Kim et al. discussed the emerging science of “global healthcare delivery,” which aims to achieve “integrated, effective delivery systems that provide value for patients,” and calls for “a rich set of heuristics to enable the tailoring of delivery strategies to local circumstances.”54 As a very general and widely applicable frame of reference for examining health care systems, the CCM, as introduced using improvement methods, is essentially a heuristic method of: 1) identifying specific barriers to optimizing health outcomes over the course of a disease cycle and 2) stimulating problem-solving in the context of individual service delivery systems.

VI. CONCLUSIONS

Over the past two decades great strides have been made in improving the lives of people throughout the world though delivery of health care services, yet high-quality health care remains nearly inaccessible to large populations. As health care challenges are examined and addressed, health care experts and planners must take care to negotiate the benefits and consequences of globalization as it pertains to health care. This means that models and methods developed and applied in high-income countries must be carefully considered, tested, and adapted or rejected in the context LMICs where they may seem useful. Meanwhile, improvement efforts and delivery science must enable the development of home-grown, locally adapted solutions to health system deficiencies. The CCM has an extensive and convincing evidence base regarding its utility in a wide variety of settings. This model and related models and principles of health care delivery are increasingly shaping the direction of health care in both high- and low-income countries. While broader frameworks and specific interventions informed by these models must be tailored to each context, the basic principles of the CCM can lead to high-quality care that is patient-centered and adapted to local conditions.

HCI-guided efforts to apply CCM principles to health care improvement in LMICs have yielded positive results in terms of health care delivery processes as well as patient outcomes. These principles appear relevant in the contexts of strengthening both core HIV care and treatment services and integrating them with essential primary care services. Due to the complexity of CCM interventions and to the difficulty of applying scientific rigor to examining improvement interventions in general, especially in low-resource settings, many of our conclusions regarding use of the CCM remain speculative. However, controlled trials to further evaluate the effectiveness of the CCM are underway in Uganda. This should help establish a more solid evidence base on application of the model in LMICs which will guide further use and adaptation of the model in these contexts and contribute to growing evidence on the effectiveness of improvement interventions in LMICs.

HCI experiences to date, along with existing evidence from higher resource settings, suggest that the principles of chronic care as described by the CCM: are so fundamental to the provision of high-quality, modern health care services for chronic illnesses that the model is as applicable in LMICs as it is in higher income countries and applicable in a variety of contexts, including the integration of primary care services such as nutrition and palliative care. Moreover, we found considerably greater impact when relevant components of the CCM were applied harmoniously at all levels of the health system.
VII. REFERENCES:


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34. Gifford AL and Groessl EJ. Chronic disease self-management and adherence to HIV medications. JAIDS. 2002; S163-166.


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## SELF-MANAGEMENT SUPPORT

<table>
<thead>
<tr>
<th>Change Concept</th>
<th>(A) IMPROVE PATIENTS’ KNOWLEDGE, SKILLS, &amp; CONFIDENCE</th>
<th>Changes/How-to</th>
</tr>
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</table>
| Educate patients about their condition(s) | Health worker or expert patient (EP) assigned to facilitate education sessions on scheduled day  
  - EP assigned for education sessions must receive guidance and supervision from health worker  
  - Begin education sessions with assessment of patient’s health knowledge using scale of 1 – 5  
  - After the assessment, the education session is tailored to address identified gaps in patient knowledge  
  - Brochures translated in local language with information about patient’s condition | |
| Facilitate sharing among patients | Identify expert patients (EPs) that are willing to share personal testimonies about their health challenges  
  - Assign them a specific date to share their experiences during a scheduled session facilitated by a health worker  
  - At the end of each session, health worker encourages other patients to ask questions and share key messages from the session  
  - Health worker summarizes messages at the end of the session | |
| Teach patients about their drugs | Identify patients on the same drug regimen  
  - Provide group sessions on the drugs and side effects  
  - Encourage patients to ask questions | |
| Provide post-test patient counseling and education | Schedule all patients newly diagnosed with HIV for health education sessions, and send them to a counselor or nurse for their first counseling session  
  - Allow them two weeks to process the information discussed during counseling, prior to starting their ART, if they desire  
  - Patients who choose to receive their care elsewhere are given a referral to another clinic, a supply of septrin, and recommendations on a reasonable timeframe for enrolling in treatment | |
| Conduct health worker-guided patient discussions | Identify a group of patients with similar health challenges  
  - Give the patients with similar challenges a common appointment date and invitation to participate in self-management groups  
  - During group appointment, health worker introduces topic and encourages discussion  
  - Health worker offers guidance during patient discussion as needed | |
| Display patient education materials | Identify important patient education materials (such as signs and symptoms of DM/HTN, nutrition information, conversation maps, WHO clinical staging criteria). | |
| Instruct counselors to assess patients’ knowledge about chronic conditions and ART | During QI team meetings, assign a counselor to assess patients knowledge about their disease(s) so that:
- Patients who are identified as very knowledgeable may be invited to serve as expert patients
- Patients who are less knowledgeable are scheduled for health education sessions |
| Use self management tool to help patients establish goals, assess patient progress on goals, and enable regular follow-up | Health workers attach a self-management tool to patients’ cards to remind health workers to review goals set at previous visit
- Prior to patient’s arrival at clinic, a counselor reviews patient files to identify those who have set goals and sets them aside at triage for follow-up with the patient
- During follow-up visits, counselors and patients review the patient’s previous goals. If previous goals are met, new goals are established.
- Include a column on the self management tool to score and record the patients’ progress on set goals |
| Establish routine self-management sessions to address specific barriers to chronic care | For defaulters:
- Counselors or triage nurse identifies “defaulters” (those patients who have missed appointments) and refer them to adherence counselors
- Adherence officers assemble defaulter groups and hold discussions to discuss reasons for defaulting and possible ways to address challenges of keeping appointments
- Patients make action plans with help from health worker who records and follows up on plan |
| | For patients with adherence challenges:
- Patients with adherence problems are identified and sent to an adherence officer/staff member
- The adherence officer helps patients to identify a cause for poor adherence and helps develop an individual action plan
- Details of action plan are recorded on a self management tool
- During the next visit, action plan is reviewed with the patient |

**CHANGE CONCEPT (B) DEVELOP SOCIAL SUPPORT SYSTEMS**

<table>
<thead>
<tr>
<th>Change Idea</th>
<th>Changes/How-to</th>
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</table>
| Identify and use expert patients (EPs) to support self-management | During health talks, health workers identify expert patients (EPs) by looking for those who are interested, active, knowledgeable, motivated, skilled as well as those who have stayed at the same clinic for at least one year
- Health staff orient EPs and provide them with key messages and ways in which they can support fellow patients
- Health workers schedule specific dates for EPs to work in the clinic and supervise EPs as they provide health education talks, retrieve files, give testimonies on clinic days, and educate other patients
- Some EPs work with patients to set goals
- EPs counsel patients by sharing experience and success stories |
| Use community health workers and expert patients (EPs) to follow-up with patients who missed their appointment | ▪ EPs discuss importance of disclosure and ways to disclose to spouses, children, and friends  
▪ Active CHWs and EPs are identified in each community  
▪ Appointment book is used to generate a list of patients lost to follow-up  
▪ Assign patients to CHWs and EPs who follow-up with the patients who live in their community  
▪ CHWs and EPs report feedback from follow-up home visits |
| Form peer-to-peer social support groups | ▪ Patients liaise with local NGO in their community  
▪ HIV positive patients who attend the same clinic form a committee headed by a chairperson  
▪ The committee identifies members who have not attended the clinic and follows-up with them in the community |
| Recommend that patients have two treatment supporters before starting ART | ▪ Patients who enroll and fail to return for the next appointment should be asked to identify two treatment supporters to establish an alternative contact in the event that the clinic experiences difficulty contacting one of them  
▪ Of the two treatment supporters chosen by a patient, one of the them must be living within close proximity to the patient’s residence |

### DELIVERY SYSTEM DESIGN

<table>
<thead>
<tr>
<th>CHANGE CONCEPT</th>
<th>(A) PATIENT RETENTION</th>
<th>Changes/How-to</th>
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<tr>
<td>Change idea</td>
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</table>
| Use an appointment book to monitor patient attendance at specific service points | ▪ Create an appointment book (if not already available) and add relevant columns based on indicators of interest  
▪ On the day of the clinic, the book is placed in the dispensing area or triage where the dispenser/nurse checks off the names of patients who have come to pick up their drugs and/or see clinician  
▪ At the end of the clinic day, the responsible staff tallies expected appointments, kept appointments and missed appointments  
▪ Patients who miss their appointments are followed up by expert patients or CHWs so that they can return for medicine and care  
▪ Appointment book is reviewed the day before patient’s appointment so that files can be retrieved in advance |
| Conduct patient follow-up visits/calls | ▪ Ensure patients provide contact information plus that of treatment supporter at enrollment  
▪ Assigned health workers to call patients who fail to make appointments and/or visit patient homes for those who live close to clinic  
▪ When following-up on the telephone, health workers ask patients on ART about side effects |
| Provide transportation for health workers to follow-up with LTFU patients | ▪ Share the following information when requesting transportation support from management:  
  o # of patients lost to follow-up  
  o Patient follow-up plans  
▪ When transport is available, schedule health team to visit patients who |
<table>
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<tr>
<th>Change Concept</th>
<th>(B) Clinic Efficiency</th>
<th>Changes/How-to</th>
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</table>
| Establish clinic days dedicated to each chronic condition and arrange for specialty care | ▪ Designate specific days and rooms for chronic care clinics  
  o Hospitals may have 2 to 4 clinic days per week.  
  o Health centre IIIs that just started to provide ART, may have one clinic day a month  
  ▪ Vulnerable groups are given another clinic day in addition to the general ART clinic day  
  o One facility sets aside a family clinic day at the ANC clinic twice a month. After delivery, HIV positive mothers are advised to come back on the family clinic day with their exposed infants  
  o One facility identifies pregnant HIV positive mothers in the ART clinic and sends them to the PMTCT/EID clinic which is held daily  
  o One facility holds EID care at the ART clinic and PMTCT in the ANC clinic. When the mother comes for PMTCT the child’s file is also retrieved from the ART clinic so that both the mother and child can be evaluated simultaneously  
  ▪ Segregate DM/HTN and HIV patients from the general OPD and arrange for specialty care  
  o Designate sections of the facility solely to run an HIV clinic on specific days of the week (i.e. those that do not have many activities or special clinics)  
  o Another day is designated as a clinic day for DM/HTN patients  
  ▪ Assign staff to work on the DM/HTN or HIV clinic day | |
| Measure waiting time using patient flow charts to address delays in servicing patients | ▪ Design a patient flow tool to help determine how long a patient spends at each service point  
  o Patient flow tools are used periodically (e.g. quarterly or every six months) to identify potential areas for delay and to improve overall service delivery.  
  ▪ Sample patients (approximately 5) during their visit and determine how long it takes them to pass through each service area.  
  ▪ Obtain timed samples twice a week for a month to determine the average patient wait times in that month  
  ▪ Use expert patients, nurses, or other health workers to collect this data  
  ▪ Determined service points where delays were greatest  
  ▪ Target interventions to reduce long wait times based on this data at these service points | |
| Triage patients with DM/HTN | ▪ DM/HTN patients are identified and directed at reception area  
  o Using the patients’ unique identification numbers, DM/HTN patients are identified and sent directly to DM/HTN clinic | |
| Move drugs/services to same location for easy access and convenience for patients | ▪ Drugs were moved from the central pharmacy to the respective clinics to alleviate crowds and prevent delays in dispensing medications to patients  
  ▪ Necessary equipment for drug dispensing acquired  
  ▪ Area where drugs stored secured and prepared  
  ▪ Staff and patients informed about the changes | |
| Capture OPD patient | ▪ Provide patients with OPD numbers from the ART clinic not from central OPD registration point in hospital  
  ▪ Introduce a register to track patients daily attendance | |
| numbers at the registry kept in the clinic | ▪ Inform patients that they will be registered at the clinic and not from OPD registration point  
▪ Register all patients who attend the clinic  
▪ Keep registers in each of the respective clinics  
▪ Allow the central registry to access daily attendance whenever necessary |
|---|---|
| Review files to prepare for patients appointment one day in advance | ▪ Using the appointment book, one staff identifies patients due for appointment and retrieves patient files a day before they are scheduled to arrive to prevent delays in locating files after the patient has arrived and to reduce patient waiting time.  
▪ The day before an appointment, CD4 counts in patient files are reviewed to find those eligible for ART  
  o A copy of CD4 results are attached to the patient’s file, so clinicians can discussed ART eligibility with patients during their clinic visits  
For DM:  
  o In the DM clinic, patient files are reviewed to determine if a fasting blood sugar is needed  
  o If so, patients are requested to come in early and are told about the importance of fasting for their appointment  
  o For eligible patients FBS test is done |
| Task shift: Assign a nurse to record patient details at triage | ▪ Patient files are retrieved by a nurse prior to the patients’ appointment in the ART clinic and are made available at triage.  
▪ Upon patient arrival, the nurse documents the purpose of patient’s visit and vitals (blood pressure, temperature, opportunistic infections, weight, MUAC, TB intensified case finding, etc.) and directs them to the appropriate clinic. |
| Assign appropriate tasks to expert patients | ▪ Active expert patients were identified to assist during clinic days with:  
  o One-on-one counseling  
  o Group health education  
  o Sharing experience and success stories with other patients  
  o Organizing, retrieving, and distributing files  
  o Triaging patients |
| CHANGE CONCEPT | (C) MONITORING & EVALUATION |
| Change idea | Changes/How-to |
| Use an appointment book to track patient’s clinical data and outcomes | ▪ Patients transport own files to the pharmacy  
▪ The nurse records the patient’s next appointment date in the appointment book as drugs are dispensed to the patient  
At two facilities:  
▪ Once the patient has been seen by a clinician, the treatment book is taken to the expert patient  
▪ The expert patient fills in details of the day’s treatment and comments on whether follow-up is needed  
At one facility:  
▪ Book is filled in by a volunteer. After the patient sees clinician, they go to the triage nurse who provides the patient with an OPD number  
▪ The patient proceeds to the pharmacy for drugs and leaves his/her file there  
▪ The data clerk retrieves files; volunteer captures return dates and copies them into appointment book |
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<tr>
<th>CHANGE CONCEPT</th>
<th>(D) CONTINUITY OF CARE</th>
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<tbody>
<tr>
<td>Change idea</td>
<td>Changes/How-to</td>
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| Assign specific tasks to staff in the chronic care clinic | - In a QI meeting, decide to attach specific staff to work in the clinic to:
  - Set goals with patients
  - Review patient records during the clinic
  - Design a duty roster for the HIV clinic staff which outlines duties that each staff are responsible for
    - Responsibilities alternate from month to month
    - Assign a person to check that staff who are scheduled to be on duty are available
  - One staff reviews patient files and when the patient returns to the clinic, they assigned to see staff assigned to address their health issues |
| Refer DM patients to higher level facilities as needed | - HC III facilities without glucometers conduct a urinalysis for patients to test for DM
  - Send patients found with trace glucose levels in their urine to a hospital along with their test results and medical history
  - Give a referral card containing clinical information to patients who develop complications or are not improving to go to a regional hospital |

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<tr>
<th>CHANGE CONCEPT</th>
<th>(E) CARE ACCESS &amp; IMPROVED SERVICE DELIVERY</th>
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<tbody>
<tr>
<td>Change idea</td>
<td>Changes/How-to</td>
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</table>
| Provide adherent and stable patients with the option to receive bi-monthly ARV refills | - Identify stable and adherent patients when they return for drug refills
  - Ask them if they would like to get two month refills and if so, prescribe them a two-month ARV supply (Emphasize the importance of patients returning to the clinic in the third month)
  - Those who are non-adherent and with low CD4 counts are given weekly appointments. Under close monitoring, these patients are gradually given appointments that are further apart (every 2 weeks, 3 weeks, 1 month, etc) until stable (i.e., improved ambulatory status, increasing or stable weight, no new opportunistic infections, etc.) |
| Offer discounts to DM patients | - Present records to administration on patients who are not returning for care due to costs associated with clinic visits (i.e., transportation, consultation, and/or treatment costs)
  - Ask administration to reduce user fee for DM patients
    - In Buikwe Hospital, administration agreed to reduce the cost of treatment and consultation fees by 50% of the normal cost in order to encourage patients to return |

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<tr>
<th>CHANGE CONCEPT</th>
<th>(F) FACILITATE SELF-MANAGEMENT SUPPORT FOR PATIENTS</th>
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<tr>
<td>Change idea</td>
<td>HOW TO GUIDE</td>
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</table>
| Provide structured health education on every clinic day and individual counseling sessions depending on patient needs | - Assign a staff member the responsibility of providing health education to patients every clinic day.
  - Design a duty roster to show when staff members are scheduled to conduct health education to patients
  - Every staff conducts health education session as scheduled
  - After a health education session, patients visit a clinician who assesses their need for an individual counselor depending on the presenting conditions (e.g., issues with adherence, missed appointments, alcoholism, weight loss, etc.) |
### CLINICAL INFORMATION SYSTEMS

<table>
<thead>
<tr>
<th>CHANGE CONCEPT</th>
<th>(A) IMPROVED DATA MANAGEMENT</th>
<th>Changes/How-to</th>
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<td>Change idea</td>
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<tr>
<td>Establish a filing system</td>
<td>▪ Share patient data with facility management and lobby for individual patient files (i.e., ask management to purchase files) to start a filing system</td>
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<td></td>
<td>▪ Assign patients unique identification numbers upon registration</td>
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<td></td>
<td>▪ Different color files are used for different patients. (Patients with DM/HTN are assigned one color file (i.e. green). Similarly, patients with HIV are assigned another color file.</td>
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<td>▪ Organize patient files chronologically/numerically/ alphabetically and place in separate filing cabinets for easier retrieval</td>
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<tr>
<td>Assign staff to update registers and other data collection tools on a regular basis</td>
<td>▪ At a QI meeting assign one person the responsibility of ensuring patient information is entered into the data tools</td>
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<td></td>
<td>▪ Assign specific staff to review and update registers on a regular basis (either daily, weekly, quarterly depending on patient volume)</td>
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<td></td>
<td>▪ Provide staff with on-the-job training on how to update the registers and agree on when register should be updated</td>
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<td>▪ Assign a team (i.e. the data team) of health workers within the clinic, the role of monitoring and preparing reports using this data</td>
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<td></td>
<td>▪ Schedule meetings for the team to review, analyze the data, and make adjustments as necessary</td>
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<td></td>
<td>▪ Share the data/ information so that all clinic staff become knowledgeable and can use data to implement changes</td>
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<td></td>
<td>▪ Refer to the appointment book to identify patients who did not come for drug refills</td>
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<tr>
<th>CHANGE CONCEPT</th>
<th>(G) ART ACCESSIBILITY</th>
<th>Changes/How-to</th>
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<tr>
<td>Change idea</td>
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<tr>
<td>Extend care/treatment services to reach patients in more remote locations</td>
<td>▪ Discuss with the unit management that you want to extend ART services to lower level facilities</td>
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<td>▪ Seek the support of the lower level facilities</td>
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<td></td>
<td>▪ Devise an outreach schedule and discuss with the facilities</td>
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<td></td>
<td>▪ On scheduled days send team to provide ART at outreach facility</td>
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<td></td>
<td>▪ Engage the team at the lower level facility in helping to provide HIV care and treatment during outreach</td>
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<td></td>
<td>▪ Share the data/ information so that all clinic staff become knowledgeable and can use data to implement changes</td>
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<tr>
<th>CHANGE CONCEPT</th>
<th>(H) PREVENTATIVE HEALTH SCREENING</th>
<th>Changes/How-to</th>
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<tbody>
<tr>
<td>Change idea</td>
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<tr>
<td>Assess all patients for sign/symptoms of DM/HTN</td>
<td>▪ Assess all patients for HTN</td>
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<td>▪ A nurse is assigned to take BP for all patients who come to the facility.</td>
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<td>▪ This is done at triage as patients are being registered</td>
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<tr>
<td></td>
<td>▪ Assess all patients for signs/symptoms of DM and complete a random blood sugar (RBS) if necessary</td>
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<td>o The clinician assesses the patients for 5 signs/symptoms of DM.</td>
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<td>▪ If the patient experiences 3 out of the 5 symptoms (i.e., polyuria, polydipsia, polyphagia, weight loss, fatigue), the clinician orders a random blood sugar test for the patient</td>
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</table>
**period to capture updated information**
- Review patient files for contact details, phone number, home address
- Identify resources available for following-up with patients.
- Assign a VHT to follow-up with the patient if one is available within the patient’s village. Ensure that there is a record of VHTs contact information.
  - Make follow-up phone calls
  - Conduct home visits using ‘maps’ (some health workers draw maps to patient’s home so that VHTs and expert patients are able to find homes)
- Summarize details regarding patient follow-up efforts and include findings in reports

**Designate one day at the clinic for data analysis**
- On the designated data analysis day, limit the number of patients given a clinic appointment
- Train staff to monitor indicators and to identify appropriate numerators and denominators
- Identify/collection data for indicators required to assess the change in question
- If missing information is discovered during the file reviews, a tag is placed in the patient’s file to remind health work to fill-in this information during the patient’s next appointment.
- Data are summarized according to the focus areas/indicators
- Team meets after file reviews to analyze the collected data and identifies areas for further improvement

**Introduce separate registers for HIV patients (instead of having them all in the general OPD register)**
- Discuss the proposed change with the administration and staff
- Acquire register from district medical stores
- Assign a specific staff member to enter patient information and update registers on a regular basis
- Provide on-the-job support to staff to ensure that register is used appropriately

### CHANGE CONCEPT (B) IMPROVE DATA CAPTURE SYSTEMS

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<th>Change idea</th>
<th>Changes/How-to</th>
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| **Use patient-held medical records** | Health workers encourage patients to purchase patient-held books
Clinicians document findings and drugs prescribed in the books
Ask patients to use the book when they go to other facilities (if not returning to the original facility) because it has all of their current information
Health workers explain to patients the benefit of buying a health books as medical forms are easily lost |

| **Use patient-held membership card to capture patient information** | Diabetic patients realized the importance of carrying information about their DM/HTN status (For example, in the event that the patients become unconscious in public, community members can assist them to get to a health facility quickly). Thus, patients requested that an identification document be provided by the facility
- A health facility was able to obtain DM cards for their patients from the diabetic clinic at the national hospital
- This membership card is carried by the patient for easy identification. It contains the patient’s name, phone number, photograph, home address, primary care facility, current medications, and date of next appointment. |
### Adapt OPD register for use as DM and HTN registers to record enrollment of patients
- Obtained generic counter book normally used as registers
- Created columns in the registers based on your indicators
- DM/HTN register included columns with clinic registration number, name, age, wt, sex, address, duration of DM/HTN, serostatus, BP, FBS, and remarks (i.e., treatment details)

### Establish system to document patient education sessions
- Ask administration blank books to document health education (These books are used to capture the following: topics covered in education sessions, the facilitator’s name, the number and name of patients who attended, and other details about patients)
- Develop lesson plans based on patients’ needs as recorded in the books

### Use tally sheets to capture counseling data
- Introduce tally sheets to help capture patient data (i.e. patients setting goals and those who made progress)
- Capture patient data on a daily basis when patients come into the clinic
- Use tally sheet to capture data focusing on different areas like: goal setting, admission, attendance, active patients, clinical data, appointment data, etc.
- Use tally sheet to make monthly reports and to plan for drugs

### Document expert patient (EP) activities
- Develop tools for patients to use in recording their activities
- Train EPs to collect and report information about patients during home visits or during health education sessions in the facility waiting area
- Document trainings that EPs have attended (i.e. counseling methods, home visits, data collection, etc.)
- Facility health worker reviews and incorporate data into the Health Management Information System (HMIS) report

### Change Concept: Clinical Monitoring

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<tr>
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<tbody>
<tr>
<td>Design DM/HTN care cards to help with patient monitoring</td>
<td>Copied care card established at another facility and adapted it to include parameters of other health facilities</td>
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**Note:** The below change was implemented by a lower level health facility (HC III) who received ART outreach support from a higher level facility (hospital):
- HC III staff agreed on a file identification system to separate patients who receive pre-ART care from those who receive outreach ART care from the hospital
- New numbers were established for all patients receiving ARVs and staff were assigned responsibilities to update patient files with the new numbers as well as update the registers.
- Patients receiving pre-ART services from HC III staff and ART outreach services from hospital staff, were transferred to receive all their care from the higher level facility outreach staff,
- Staff communicate to the patient at the subsequent visit the changes in their clinic number
## DECISION SUPPORT

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<tr>
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<tbody>
<tr>
<td>Change idea</td>
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</table>
| Provide CME sessions for staff | ▪ Different CME topics are chosen such as how to: take blood pressure, attend to patients with HTN and DM, treatment options available, etc.  
▪ Staff are notified in advance of the date, time, and location of the CME training and attendance is recorded at each meeting  
▪ CME staff facilitator is identified and conducts the CME on the scheduled day  
▪ Weekly or biweekly CMEs can be used to improve the staff’s ‘capacity to correctly fill and complete the HIV client card and registers  
▪ Identify health workers in the HIV clinic to be trained through a staff meetings  
  o Provide on-job training on the scheduled day on how to complete HIV registers and client cards and how to interpret and use the information (HIV registers and patients’ cards can be obtained from MOH or district)  
  o Meet periodically to review the data and monitor usage of these tools |                |
| Convene case conferences among health worker staff | ▪ Use the patient registry books to identify DM/HTN patients that are not responding to treatment  
▪ A staff meeting is then scheduled to discuss why the patients are failing treatment and/or how to address sign/symptoms (such as diabetic foot).  
  o The in-charge staff at the DM clinic takes a lead in inviting members to the case conference and facilitating the meeting |                |

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<thead>
<tr>
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<tr>
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<tr>
<td>Display guidelines, standard operating procedures, and flow charts to aid health workers in decision making</td>
<td>▪ Staff copied the DM/HTN section of the Uganda clinical guideline handbook and WHO HIV clinical guidelines on to flip charts and posted them on the walls in clinical rooms.</td>
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</table>
| Identify staff/health worker to administer questions about TB at triage for all HIV positive patients accessing services at the health facility | ▪ Identify health worker to be trained in TB assessment and provide orientation to use the TB Intensified Case Finding (ICF) tool  
▪ Ensure that the designated staff is available at the triage to assess patients for TB  
▪ Fill in codes into the TB section within the HIV/ART care cards and use code to determine whether further TB assessments are needed for the patients  
▪ At the end of the clinic day, summarize the number of HIV patients assessed for TB, the number of patients with suspected TB, and those sent for further investigation and laboratory follow-up |                |