Health Providers’ Perspectives on Incorporating the Chronic Care Model into the Management of Diabetes: Findings from a Community-based Hospital in Nepal

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A thesis
submitted in partial fulfillment of the
requirements for the degree of

Master of Public Health

University of Washington
2017

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Health Providers’ Perspectives on Incorporating the Chronic Care Model into the Management of Diabetes: Findings from a Community-based Hospital in Nepal

Biraj M Karmacharya

Background: Nepal is not adequately prepared to tackle the increasing burden of diabetes, largely due to the lack of clarity on the integration of chronic disease management into health care delivery. Clear understanding of the opportunities and challenges of incorporating proven models of chronic disease care, such as the Chronic Care Model (CCM), into diabetes management is vital for any effort to improve diabetes care.

Objectives: We aimed to: 1) describe the existing approach to diabetes management in Dhulikhel Hospital (DH), a community-based hospital in Dhulikhel, Nepal; 2) identify the opportunities and challenge of incorporating the components of the CCM into diabetes management at DH; and 3) develop a comprehensive plan for incorporating components of the CCM into diabetes management at DH.

Methods: This cross-sectional mixed-methods study included qualitative and quantitative data collection strategies. We administered the Assessment of Chronic Illness Care Version 3.5 to obtain the perspectives of hospital leadership (n=2) and health providers (n=27) on the status of diabetes care at DH. Following a presentation of the CCM, we conducted in-depth interviews
with hospital leadership (n=2) and health providers (n=8) to obtain their perspectives of the opportunities and challenges for incorporating CCM components into diabetes care. Findings were synthesized to develop a set of recommendations.

**Results:** The overall score for the Assessment of Chronic Illness suggested stakeholders to perceive the presence of basic support for chronic disease (overall median program score of 5.4, IQ range: 2.8) at DH. There was consensus among the participants that CCM was highly relevant and important. Almost all of them said that the existing system addressed most of the components of CCM and believed that the ongoing activities and platform of DH provided opportunities for incorporating components of CCM into diabetes management. The components of delivery system design, decision support and organization of health care were considered already present in some form. However, there were concerns from the participants in the areas of community resources, self-management support and clinical information system.

**Conclusion:** Recommendations based on data collected here provide feasible actions that may be taken at the leadership and provider level to improve diabetes care and management in Nepal. Many of these recommendations may be relevant to other low-income countries hoping to utilize the CCM for addressing the burden of diabetes and improving patient outcomes.
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<th>Description</th>
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<tr>
<td>CCM</td>
<td>Chronic Care Model</td>
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<tr>
<td>CVD</td>
<td>Cardiovascular Diseases</td>
</tr>
<tr>
<td>DH</td>
<td>Dhulikhel Hospital Kathmandu University Hospital</td>
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<tr>
<td>DHS</td>
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<td>EMR</td>
<td>Electronic Medical Record</td>
</tr>
<tr>
<td>IQ</td>
<td>Inter-quartile</td>
</tr>
<tr>
<td>LMIC</td>
<td>Low- and Middle- Income Countries</td>
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ACKNOWLEDGMENT

I have always believed that epidemiology is the pursuit of truth and global health is the application of the knowledge of truth in real world settings. This led me to take this ‘road less travelled’ to pursue MPH in Global Health (Leadership, Policy and Management) after my PhD in Epidemiology. The Department of Global Health at the University of Washington, with its team of unparalleled faculties, staffs and truly global student community (not just in terms of nationality, but also in terms of mentality) made my time as a student memorable and inspirational period of my professional career. I have forged relationships that stand higher than any degree or certificate.

I have been incredibly fortunate to be guided by Prof. Annette Fitzpatrick, whom I consider as an ideal mentor, who puts all her efforts to ensure the overall growth of the mentee. I was also fortunate to be advised by Dr. Nona Sotoodehnia and Dr. Bryan J Weiner, who provided expert opinion and continuously pushed me to think beyond the boundaries. Dr. Sotoodehnia, who is also my mentor for post-doctoral training, has helped me understand the value of perseverance, positive outlook and untiring dedication for one’s work.

I have also been blessed to have very supportive family members (dad Raj Bhai, mom Bindu, brothers Rajiv and Robin, sister Ruby, sisters-in-law Meeta and Resha, nieces Rebisha and Myra, and all my relatives) who never fail to fill my heart with hope and enthusiasm. My wife Angira and son Abiral stood by my side all the time, without any complaint – in times of joy and in moments of despair; during days while I was ‘lost’ in my work at home or the holidays they had to sacrifice because of my deadlines. They left everything they had back home to accompany me in seemingly unknown and uncertain world. I have learnt from them the value and strength of love.
Dhulikhel Hospital and the Department of Community Programs families always inspired me to achieve higher. Special thanks goes to Dr. Abha Shrestha, Mr. Prabin Shakya and Ms. Sachita Shrestha who were the integral part of this research work. All my friends and acquaintances in Seattle made me always feel at home. The memories I share with Binod and Archana are special. Archana, an epitome of determination and dedication as well as sincerity and simplicity, has been my closest friend, most honest critic, wisest guide and an exceptional ally. Abebe Aberra has been a dear friend who first showed me the path to Global Health and continues to make me critically and constructively think all I do.

I am also deeply indebted to the Fulbright Program for providing opportunity to join University of Washington. I also thank University of Washington Global Opportunities (GO) Health Fellowship that supported my field work for this research. Prof. Carey Farquhar, whom I had the privilege to work for, continuously supported my academic pursuits. Finally, my humble gratitude to all the participants of this study – whose noble efforts I aim to complement, even if it is by a tiny fraction.
DEDICATION

To,

My father Raj Bhai Karmacharya and mother Bindu Karmacharya,

Who trained me to dream big.

My wife Angira Shrestha and son Abiral Karmacharya,

Who have always believed in my dreams.
INTRODUCTION

Diabetes in Nepal

With an increase of almost twenty years of life expectancy in the last four decades, chronic diseases, primarily cardiovascular diseases (CVD) and diabetes, now comprise the major disease burden in Nepal. Despite this, the country is unprepared to tackle the challenges of chronic diseases prevention and management, largely due to a lack of national level strategy and poor understanding of how chronic disease management can be integrated into health care delivery.

The prevalence of diabetes has been rising as a silent epidemic in Nepal similar to other low- and middle-income countries (LMICs). It is estimated that between 1990 to 2010 the rate of diabetes has increased by 89% in Nepal.\(^1\) Shrestha et al. (2006) reported a 19% prevalence of diabetes among adults (≥ 40 years) residing in urban Kathmandu.\(^2\) The latest WHO STEPS survey on non-communicable disease (NCD) risk factors showed that among 15 to 69-year-old Nepalese adults, nearly 8% of the participants had impaired or high fasting blood glucose.\(^3\) Among people aged 40 years and older in urban areas, the prevalence of diabetes was found to be 19%, and more than half (54.4%) of the diabetics in a separate study were unaware of their diabetes status.\(^2\) In a recently conducted study in Dhulikhel Hospital, among 343 diabetic patients on treatment, only 37.4% had HbA1C level under control.\(^4\)

Nepal is also facing the consequences of urban lifestyles leading to increases in obesity and the metabolic syndrome. The first nationally representative study, the Nepal Non-Communicable Disease Risk Factor Survey (NCDRFS), was conducted in 2007 among 15 to 64 years old adults and reported 7% overweight, 1.7% obesity, and 10.8% self-reported diabetes. Obesity increased in Nepalese women (15 to 45 years old) from 1.6% in 1996 to 10% in 2006.\(^5\) A survey in the eastern region of Nepal reported 6.7% prevalence of diabetes and 32% prevalence of obesity among adults of 20 years or older.
This study also reported that almost 20.7% of those surveyed had metabolic syndrome using NCEP ATP III criteria.6

**Existing Gaps in Diabetes Prevention and Management**

Existing disease prevention and management programs in countries like Nepal suffer from major gaps related to diabetes. **First,** there is no national level program and policy in place for diabetes prevention and management. **Second,** there is negligible activity to make communities aware of diabetes and no regular screening programs are in place. **Third,** when diabetes is diagnosed, treatment is usually provided in health facilities that do not have a coordinated system of diabetes management. For example, most health facilities do not have a structured medical system and are characterized by a poor medical records system, absence of follow-up, and lack of coordination for referral to specialized disciplines for consultations on complications, resulting in poor quality of care. In a recent national survey of health facilities in Nepal, only one in five offered services for diabetes that included diagnosis, prescription of treatment, or management of diabetic patients. Among facilities offering diabetes services, only 4 percent had guidelines for the diagnosis and management of diabetes. Only 2 percent had a staff member recently trained in provision of such services.7 **Fourth,** there is no system in place in the communities for supporting diabetes self-management.

**Innovative Approaches to Diabetes Management**

Although there are evidence-based approaches to prevent and manage diabetes and its risk factors, there are still major gaps in the implementation of these methods especially in LMICs. This is compounded by the fact that chronic diseases such as diabetes need a structured, well-concerted comprehensive approach comprised of on-going prevention activities, timely screening, standard clinical management, and self-management skills for life-style modification. Unfortunately, the existing health system in Nepal (similar to most other developing countries) is not prepared to address these challenges. There is no
national policy or strategy to address diabetes in the current health system. Lack of standard national guidelines and protocols is another hindrance for effective prevention and management of diabetes. Although organizations like the Nepal Diabetes Association, Nepal Diabetes Society, and Diabetes and Endocrinology Association of Nepal have engaged in advancing diabetes prevention and management programs, many challenges remain and significant changes in health care delivery are needed.

One of the promising approaches to improve diabetes care is integration of the Chronic Care Model into the health system. The Chronic Care Model (CCM) is the best-known model for chronic disease management.\textsuperscript{8,9} It focuses on linking informed, actively engaged patients with proactive and prepared health-care teams.\textsuperscript{10-14} This model involves a collaborative approach in the following six core areas: health systems (organization of care), clinical information systems, delivery system design, decision support, self-management support and community resources.\textsuperscript{10-14} In a review of CCM-related studies published since 2000, authors reported that evidence suggests practices redesigned to fit the CCM generally improved the quality of care and the outcome for patients with various chronic illnesses. There was also evidence indicating that interventions incorporating multiple elements of the CCM had better outcomes than those with fewer elements. In a systematic review of CCM implementation for type 2 diabetes, 6 of 14 studies (43\%) provided evidence of effectiveness of the CCM for type 2 diabetes management in primary care as well as significant improvement in clinical outcomes.\textsuperscript{15}
Rationale for this Study

The evidence for use of the CCM for diabetes management has been based primarily on findings from developed countries. None of the 14 studies included in the aforementioned systematic review of the CCM for type 2 diabetes were conducted in developing countries.\textsuperscript{15} It is vital to understand the opportunities and challenges of incorporating the components of CCM into a low-income setting before preparing implementation plans. We aimed to utilize an institutional setting of a community-based hospital in Nepal, Dhulikhel Hospital, to explore these challenges.

Dhulikhel Hospital (DH) is a pioneer community-based hospital founded with the principles of social equity and the mission of ‘quality health service to the poor’. Since there is no government-run tertiary hospital in the vicinity, it serves as the only tertiary hospital for the districts of Kavrepalanchowk, Sindhupalchowk, Dolakha, Ramechhap, Sindhuli serving a catchment population of about 2.1 million. DH is officially registered in the Social Welfare Council of the Government of Nepal as a non-profit organization. It collaborates extensively with the government in the development of health policies and in advancing health services and health sciences education in the country. In addition to its role as a tertiary-level university hospital, DH has developed a network of 21 rural community-based health service providers supported as outreach centers within its referral network. It thus resembles a ‘microcosm of a health system in resource-limited settings’. Therefore, DH provides a unique opportunity for developing and testing new models of health service delivery in LMICs. Furthermore, DH is a tertiary hospital with a dedicated diabetes clinic, has experts required in diabetes care (e.g., nutritionist, physiotherapist, ophthalmologist, etc.), and has an established history of running community-based health care with systematic referral mechanism. It is thus uniquely positioned to test the implementation of the CCM for diabetes management.
OBJECTIVES OF THE STUDY

The objective of this study was to identify the opportunities and challenges of incorporating the components of the CCM into diabetes management within Dhulikhel Hospital, a community-based hospital in Nepal.

Specifically, we aimed to:

1. Describe the existing approach to diabetes management in Dhulikhel Hospital (DH);

2. Identify the opportunities and challenge of incorporating the components of the CCM into diabetes management at Dhulikhel Hospital (DH); and

3. Develop a comprehensive plan for incorporating components of the CCM into diabetes management at Dhulikhel Hospital.
METHODS

Study Design
This was a cross-sectional mixed method study that included qualitative and quantitative data collection strategies.

Study Setting
This study was conducted in Dhulikhel Hospital Kathmandu University Hospital (DH), a tertiary-level university hospital that provides health services to a catchment population of about 2.1 million people. Among other services, it also has a dedicated diabetes clinic and provides both outpatient as well as inpatient services for diabetes management.

Study Population and Sampling Strategy
Information on the study was disseminated during the regular morning meeting of the institution and through announcements in the wards and respective departments. Of those who showed interest, we administered informed consent to the following participants: 2 physicians who were engaged in providing diabetes care in DH for at least 2 years; 13 nurses who were engaged in diabetes care in DH for at least 2 years; 5 rural health workers; 1 pharmacist and 1 nutritionist. Additionally, we administered informed consent to the hospital director and matron (representing institutional leadership). All the above-mentioned participants provided consent to participate in the study.

Study Procedures and Data Analysis
Aim 1: In order to describe the current approach to diabetes management in Dhulikhel Hospital, we used direct observation methods by documenting the practices involved in diabetes care. A checklist was developed a priori that included information on patient numbers, facilities available for diabetes management and usage of electronic medical record (see Appendix 1).
We also administered the Assessment of Chronic Illness Care Version 3.5 (Appendix 2) to gain the perspectives of the hospital leadership and health providers described above (Nurses: 13 including matron; Clinicians: 9 including hospital director; Rural Health Worker: 5; Pharmacist: 1; Nutritionist: 1) on the status of diabetes care in DH.\(^{16}\) The median scores and interquartile range of each of the categories of the questionnaire were presented.

**Aim 2:** We included the hospital director (n=1), the matron (n=1), and several providers (3 physicians, 4 nurses and a nutritionist) involved in the management of patients with diabetes for this aim. After obtaining informed consent from the participants, we first administered the Assessment of Chronic Illness Care Version 3.5 questionnaire to gain their perspectives on the status of management of diabetes in DH (aim 1).\(^{16}\) Trained research assistants conducted in-depth interviews to collect more details on their opinions. They were asked to describe what they thought were the strengths and what were the areas for improvement. Thereafter, the research assistants made a fifteen-minute presentation on CCM and gave a hand-out for participants to review (see annex). Study participants were given the opportunity to ask any questions regarding the CCM. Following this they were asked about what they thought were the opportunities and challenges of incorporating the components of the CCM in diabetes management in DH.

All the interviews were audiotaped and transcribed verbatim into Nepali language. The recorded files were securely stored in a password-protected file in an encrypted folder that was accessible only to the researcher. No personal identifiers were mentioned in the digital files. Each interview lasted about 30 minutes to one hour. The interviews were conducted in private with no one else present. Full assurance was given before the interview that the interviewee’s comments would not in any way affect his/her job status.
We used inductive coding to identify themes from the interviews. Data were analyzed using a thematic framework method first to understand their perception on the status of diabetes management in Dhulikhel Hospital (DH) and then to identify the themes related to opportunities and challenge of incorporating the components of CCM into diabetes management at DH.\textsuperscript{17} The investigator read the transcripts several times to obtain thorough understanding of the entire discussion. The text was then divided into meaning units such as phrases and quotes and the meaning units were condensed and presented. For presentation of results, we have combined comments from the matron and nutritionist with nurses and the hospital director with clinicians to maintain anonymity in quotes below.

\textbf{Aim 3:} Based on the synthesis of the findings of the first aim, we developed a set of recommendations for incorporating the CCM into Dhulikhel Hospital’s diabetes management program. This will be shared with the hospital leadership for further discussion and future planning purposes.

\textbf{Ethical Considerations}

The study was approved by the Dhulikhel Hospital Institutional Review Committee and was exempted from University of Washington Human Subjects Division. All the participants of the study were administered informed consent prior to enrollment. They were informed about the potential lack of confidentiality when it was reasonably easy to assume the identity. They were assured that their names and identities would not be revealed in any publication or reports.
RESULTS

Current Status of Diabetes Management in Dhulikhel Hospital

Information on resources currently available for managing patients with diabetes at DH was gathered by observation and review of records from relevant clinics. Results are provided in Table 1.

Table 1: The current status of diabetes management in Dhulikhel Hospital based on observation of core services.

<table>
<thead>
<tr>
<th>Table 1. Summary of current status of diabetes management in Dhulikhel Hospital</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Health providers directly involved in diabetes care</strong></td>
</tr>
<tr>
<td><strong>Out-patient services</strong></td>
</tr>
<tr>
<td>Out-patient diabetes clinic</td>
</tr>
<tr>
<td>Average number of patients per day</td>
</tr>
<tr>
<td>Patient counselling sessions</td>
</tr>
<tr>
<td><strong>In-patient services</strong></td>
</tr>
<tr>
<td>In-patient services</td>
</tr>
<tr>
<td>Average number of diabetic in-patients on a given day</td>
</tr>
<tr>
<td>In-patient counselling sessions</td>
</tr>
<tr>
<td><strong>Others</strong></td>
</tr>
<tr>
<td>Community programs</td>
</tr>
<tr>
<td>Health records</td>
</tr>
</tbody>
</table>

Diabetes Care in Dhulikhel Hospital is organized through a dedicated Department of Endocrinology. It is run by a certified endocrinologist, 5 general physicians and two nurses. Detailed information on the provision of diabetes-related services is provided below.

Outpatient Services

Outpatient service is provided through ‘Diabetes Clinic’ that is run Sunday through Friday. Patients are referred directly from the outpatient registration or through referrals from other departments. On average about 2-4 new patients and 10-15 returning patients visit the clinic every day (six days a week). Two nurses (diabetes nurses) run group patient counselling programs at the diabetes clinic. Each group is comprised of about 15 diabetic patients and their family members. Each group counseling session lasts
approximately one hour and is conducted twice a week. Sessions area also added on the need basis. All the patients attending outpatient are recommended to participate in these group-counselling sessions. The nurses have not taken officially certified courses for diabetes counseling but have learnt and improvised their educational materials in consultation with number of visiting experts. These sessions include basic pathophysiology of diabetes, modalities of treatment, detail information on behavioral aspects of diabetes management (diet, physical exercise, life-style change, stress relieving techniques), and information on the use of medications. The hospital also has an advanced laboratory department with the facilities to perform all the tests required by the clinic. When needed, patients are referred to other departments, mainly physiotherapy, ophthalmology, and surgery and other higher centers for further evaluation of diabetic complications.

Inpatient Services

Diabetes inpatient service is provided through the inpatient department of the hospital. The patients that are admitted exclusively for diabetes-related complications are admitted as medicine inpatients. The patients that are admitted for other causes and have incidental finding of diabetes are admitted into their respective departments. All the in-patients with diabetes are managed by the endocrinologist and his team. At any given time, there are about 3-5 inpatients with diabetes in the hospital. The diabetes nurses also conduct counseling sessions in the wards twice a week and provide individual guidance to the patients that need instructions on taking insulin in in-patient wards. Other nurses in the in-patient wards also provide additional individual guidance to the patients on insulin-therapy.

Other services

There is one nutritionist who manages her time providing group as well as individual counseling to the patients in the hospital.
Community programs

There is no regular or systematic program for community awareness or screening. The diabetes nurses and the physicians occasionally participate with the Dhulikhel Diabetes Club and the Department of Community Programs in organizing community-level awareness and screening programs.

Health records

There is no systematic way of collecting health records for the patients. All out-patient information is paper-based and is owned/carried by the patients. The inpatient discharge summaries are electronic but the day-to-day clinical notes are all paper-based.

Follow-up

Patients are advised to come for follow-up based on standard guidelines. However, there is no system in place to send reminders or follow-up messages or calls to keep appointment. No comprehensive system for patient tracking is available. During follow-up visits, the patients get repeat test for blood sugar, and are also reassessed on their medications. Special emphasis is given on insulin injecting and storage practices. Depending upon the availability of the nurses, patients might also receive special one-to-one or group counseling sessions on diet, exercise and medication.

Findings from the Assessment of Chronic Illness Care

We administered the Assessment of Chronic Illness (version 3.5) to 29 participants (Nurses: 13; Clinicians: 9; Rural Health Worker: 5; Pharmacist: 1; Nutritionist: 1). Table 2 shows the summary of the scores of the Assessment of Chronic Illness (version 3.5). Figure 1 shows the box-plot of the median scores of each of the categories of assessment.
Table 1. Summary of Assessment of Chronic Illness (version 3.5) scores (n=29)

<table>
<thead>
<tr>
<th>Categories</th>
<th>Median (IQ range)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Organization of Health Care System</td>
<td>6.1(2.1)</td>
</tr>
<tr>
<td>Community Linkages</td>
<td>6.3(4)</td>
</tr>
<tr>
<td>Self-Management</td>
<td>6(2.5)</td>
</tr>
<tr>
<td>Decision Support</td>
<td>5.5(2.5)</td>
</tr>
<tr>
<td>Delivery System Design</td>
<td>4.6(2.6)</td>
</tr>
<tr>
<td>Clinical Information System</td>
<td>4.6(3.2)</td>
</tr>
<tr>
<td>Integration</td>
<td>4.6(2.5)</td>
</tr>
<tr>
<td>Overall Program Score</td>
<td>5.4(2.8)</td>
</tr>
</tbody>
</table>

**Interpretation of Scores:**
Between “0” and “2” = limited support for chronic illness care
Between “3” and “5” = basic support for chronic illness care
Between “6” and “8” = reasonably good support for chronic illness care
Between “9” and “11” = fully developed chronic illness care

Figure 1: Scores of Assessment of Chronic Illness Care in Dhulikhel Hospital
The overall score for the Assessment of Chronic Illness suggested stakeholders to perceive the presence of basic support for chronic disease (overall median program score of 5.4 (IQ range: 2.8). Participants rated community linkage and organization of health care system to have the most support with median scores of 6.3 (IQ range: 4) and 6.1 (IQ range: 2.1), respectively. Delivery system design, clinical information system and integration of the components were scored lowest with median IQ scores of 4.6.

**Findings from the Key-Informant Interviews**

We interviewed ten key informants to identify the perceived opportunities and challenges of incorporating the components of the Chronic Care Model (CCM) into Diabetes Management in Dhulikhel Hospital. These ten key informants were:

1. Hospital director (n=1)
2. Hospital matron (n=1)
3. Clinicians involved in diabetes care (n=3)
4. Nurses involved in diabetes care (n=4)
5. Nutritionist (n=1)

**Perceived status of current diabetes care in DH**

**Strengths:**

All the study participants believed that the diabetes care for the patients in the hospital was of high quality. They highlighted that the availability of laboratory facilities, clinicians practicing standard guidelines, opportunities for consultation with different specialties and strong nursing team were major assets.

‘Once the patients are inside the hospital, we take very good care of them. We can have any consultation we want. We have dedicated nurses that train them on various things including how to take insulin.’ (Nurse)
‘We follow the American Diabetes Association guidelines for the management of the patients and are sure that the care we provide is of high quality.’ (Clinician)

‘Except for few, we provide all services to the diabetic patients in our hospital. We have different specialists and a high-quality laboratory. We also have education program to the patients through nurses.’ (Clinician)

‘We involve patients in the decision making. We give them various options of treatment and ask them to choose what would fit best for them.’ (Clinician)

‘Our hospital, which is a community-based and affordable health facility, itself is a big strength for a good management of diabetes.’ (Clinician)

‘We have a good environment here in this institution. We have a focal person whom we can consult and who can guide us.’ (Nurse)

‘We have very refined materials for educating patients. We have managed to convince many patients who initially refused to take insulin.’ (Nurse)

Weaknesses:

Although the participants were confident about the high quality of care ‘inside’ the hospital, there were significant concerns regarding what would happen when the patients returned home. All were concerned that the programs being conducted at the hospital might not be sufficient for several reasons that are described below:

**Time constraint:**

The education sessions in the outpatient setting are conducted thrice a week in a group of about 15 patients and patients’ family members. These are one-time sessions running about 1-2 hours in length. All the information about diabetes and its management is condensed into this one setting. Participants voiced that ideally this should be done in multiple sessions as the information is too overwhelming for one session. However, the lack of time of the nurse educators as well as that of the patients were major hindrance to more expansive diabetes management education.

‘The patients come from far away and they are in a rush to go home. So, they cannot spend a long time in the hospital. We are also not able to know when they will come next because they are far away in rural places; and it is difficult to ask them to come
soon. We don’t know if they will keep exact appointments. Hence it is not easy to organize trainings in multiple sessions.’ (Nurse)

‘We are just two nurses here and we need to take care of the out-patient education, in-patient education, sometimes personalized education, and many other tasks. Hence, we cannot devote longer time and settings to the patients although we would love to do so.’ (Nurse)

‘I would so much like to conduct some interactive sessions, may be with some audio-visual aids, may be for a whole day and also do some demonstrations on food and food preparations. But it is not possible because the patients are in hurry and I am too tied up too.’ (Nurse)

‘The education programs in the wards and the out-patients are not daily. Although we ask the patients to come on particular day, sometimes it is impossible for them to do so and hence they miss the opportunities.’ (Nurse)

Background of the patients:

Most patients are from very poor socio-economic backgrounds and have little prior knowledge about diabetes. Educating them about diabetes in one session is challenging. Furthermore, for many patients taking insulin at home is too complicated and they are not able to follow the instructions.

‘Those who know little bit about diabetes beforehand can grasp well but we get patients who have absolutely no prior knowledge about diabetes. Educating them about the disease, medications, life-style change, etc. in one sitting is too overwhelming. It is too much for them to even listen, let alone understand.’ (Nurse)

‘A lot of our patients coming here are poor and cannot afford long-term insulin. We are also not sure if they can store insulin properly at home. They are also the ones for whom it is difficult to come for regular follow-up.’ (Nurse)

‘For most of our patients coming from rural areas, it is hard to buy, store and use insulin.’ (Nurse)

Follow-up of the patients

There is currently no resource or system in place to proactively contact the patients or provide community-based programs for diabetes. Patients cannot be tracked and there is no way to identify vulnerable population or groups.

‘Our current approach is actually a passive one. We wait for the patients to come to us. Once they come we manage well.’ (Clinician)
'We cannot arrange for door-to-door follow-up or contact to the patients. Hence, many patients, who after they feel fine might not bother to come for follow-up. Follow-up is a big problem.' (Matron)

'It would be nice if we could contact the patients for follow-up. Let us say, currently out of 100 that I call for follow-up, 20 come on time. May be after we do phone calls, 40 will come. It may not be 100 but it will definitely be more.' (Clinician)

'In emergency, we see patients that come with acute complications because they did not properly follow instructions given by the doctor. Many of them had never come for follow-up or took medications properly.' (Clinician)

**Lack of awareness and screening programs in the community**

The overall lack of awareness of diabetes in the community is another hindrance. The information from peers and community members shape the behavior of the patients. Thus, if most the community members are following behaviors that are not recommended, patients are likely to be affected by that too. There are also no regular screening programs in the communities and most of the community members do not know about their own diabetes status. This also poses difficulties in organizing targeted education programs

'We only spend a few hours with the patients and ask them to do this and do that. They go home and listen all the time to what their friends, family members and neighbors say. It is likely that they are more influenced by them. Sometimes I feel we should really do mass education campaigns and dispel wrong notions about diabetes.' (Nurse)

'We also do not have data on which population are most affected and hence have not conducted very specific awareness programs although we have some general awareness programs in the communities.' (Nurse)

'We have occasional screening programs in the communities but these are not regular. We need to make them regular. Grass-root level programs need to be organized.' (Clinician)

**Lack of locally tailored protocols**

Although there are standard clinical guidelines for patient management and education, there is still no standard locally contextual guideline available. Locally contextual guidelines would ideally consider feasible treatment options (drugs that are more affordable, accessible and do not require complex
monitoring), follow-up plans (that take into account the difficulties of coming for follow-up) and lifestyle changes (that take into account local dietary habits, physical activity pattern and other cultural issues).

‘Many of our patients cannot take insulin and are not able to come for follow-up regularly. Although we know as per standard guideline, they must take insulin and come for follow-up we are not sure what we should advise them. It would be nice if there were something that would be very appropriate for some of these patients that come to us.’ (Nurse)

**Lack of a structured system for monitoring and evaluation**

There is no structured system or data collection mechanism in place to evaluate the outcomes of treatment and education. The health providers do not have a clear idea about the quality of their performance.

‘We would really like to know how well our programs are helping or not helping the patients but we do not have a system to evaluate. We tried once but it took a long time and was not feasible.’ (Nurse)

‘We are not able to take proper feedback from patients and do not have the data to measure the performance of our activities.’ (Clinician)

**Perceived opportunities and challenges of incorporating the components of CCM in diabetes management in DH.**

There was a consensus among the participants that CCM was highly relevant and important. Almost all of them said that the existing system did address most of the components of CCM and believed that the ongoing activities and platform of DH provided opportunities for incorporating components of CCM.

The components of delivery system design, decision support and organization of health care were considered already present in some form. However, there were concerns from the participants in the areas of community resources, self-management support and clinical information system. Three themes emerged in relation to the concerns on CCM. First was the need for further training opportunities to help
providers become more aware of diabetes care. The second issue was regarding lack of resources; and the third issue addressed the background of the patients. Since most patients are from poor socioeconomic status and are from rural areas, there were some major limitations regarding follow-up, ability of the patients to grasp the information and the challenges of using mHealth platforms.

Delivery System Design

Overall the participants were satisfied about the current approach of the DH delivery system, which is comprised of physicians taking care of the diagnosis and clinical management whereas nurses are involved in the counseling and behavioral interventions. However, the nurses involved in current diabetes counseling suggested that other nurses mainly involved in the in-patient care of diabetes patients could be further trained in patient counseling to share and reinforce diabetes management. They suggested it would also help ensure that all the patients in the in-patient care would be able to get counseling sessions. One clinician also suggested that the roles and responsibilities of various health service providers could be better defined and coordinated so that the care delivery could be better organized.

‘Generally only two of us conduct diabetes education program for the patients. We could train other nurses in the wards to do that and hence that will save a lot of time for us to do other things.’ (Nurse)

‘There are different health service providers (nurses, physicians, physiotherapists, surgeons, etc.) involved in diabetes care. We could clearly define their roles and responsibilities and arrange for a better coordination.’ (Clinician)

Decision Support

The clinicians were satisfied with the existing system for using guidelines in the clinical management. They reiterated that standard ADA guidelines were being followed for patient management. One clinician mentioned the need to develop a standard protocol for the management of diabetes in rural settings, mainly through the DH outreach centers. The nurses mentioned that there was a need for a
more tailored version of management protocol, both medical and behavioral that would be suitable for the patients primarily residing in rural Nepal where they had little access and ability to follow to the standard treatment regimens.

‘We should further revise the patient education materials, self-management information and some treatment protocols that would fit to our patients from rural areas.’ (Nurse)

‘We are preparing a protocol for the rural health providers. It will be helpful.’ (Clinician)

There was also emphasis on a focus for continued professional development opportunities for strengthening the capacity of the health providers to align with the CCM approach.

‘These days health services have become very specialized. We need to train the nurses very well and offer them advanced professional opportunities if we really want to make them excel in diabetes care.’ (Nurse)

‘We are doing well but we still need further training and exposure to learn about latest updates and see how things are done in other places.’ (Clinician)

‘Our health professionals have been trained very differently in terms of management of patients. We really need to rethink about how we train them even when they are students so that they get better idea about the approaches of CCM.’ (Clinician)

**Organization of Health Care**

There was considerable confidence regarding institutional leadership support for newer endeavors to improve management of diabetes.

‘We have a unique opportunity to connect with the rural health workers when the doctors visit the outreach centers. We could use that to identify known and at-risk individuals and help organize some training and service programs in the rural clinics.’ (Clinician)

‘Chronic Care Model is appropriate and feasible for our hospital. We adapt changes easily and there is no hierarchy and bureaucracy here. So, we will be able to implement this.’ (Clinician)
Community Resources

The participants highlighted that DH had a unique opportunity to conduct programs in the community because of its outreach centers and its connection with the local community in Dhulikhel. A community-based organization called Dhulikhel Diabetes Club had been recently formed by a group of local diabetic patients with the aim of organizing local diabetes awareness, peer-support and screening programs. DH had started to collaborate with the members in organizing awareness and screening programs.

‘We have health programs in rural areas through the outreach centers. So, it is lot easier for us to do in the communities. We are also already working with a local diabetes club for diabetes education and screening.’ (Nurse)

‘We can improve care by linking with our community centers and tracking patients.’ (Clinician)

‘We can partner with the Diabetes Club in the Dhulikhel with whom we have already started collaborating.’ (Nurse)

However, the participants emphasized that cost of running a dedicated program for community engagement would be a major issue because it required additional staff.

‘It is technically possible to organize activities in the communities and arrange follow-up. However, we need additional staffs and resources to do this. We cannot do by ourselves as we are already overstretched.’ (Clinician)

Self-management Support

There were significant concerns among the participants about the capacity to train patients on self-management skills. Whereas many felt reassured about the ability of patients from urban areas to follow most of the self-management recommendations, there were serious doubts about the patients who came from rural areas.

‘The baseline knowledge of diabetes among patients is very poor, virtually nil. It takes a long time for us to make them prepared for self-management. That can happen only in several settings and it is hard to ask the patients to come for follow-up many times.’ (Nurse)
Clinical Information System

All believed that an advanced clinical information system and an ability to detect patients for follow-up, send reminders, initiation of newer tools would be of advantage. However, there were major doubts about whether that would be possible given the amount of resources they required. Since most patients are from poor socioeconomic status and are from rural areas, there were some major limitations regarding follow-up, ability of the patients to grasp the information and the challenge in using mHealth platforms.

‘Existing details of the patients are maintained only in register and are not electronic. Hence, they are not easily retrievable, usable or shared to different departments. EMR would help address this but it will be very costly.’ (Nurse)

‘CCM is good and appropriate but we need to design in a very smart, cost-effective way.’ (Clinician)

‘Many of our patients do not use smart phones. Thus, we will not be able to use apps or even sms. Maybe we can do that for patients living in cities.’ (Clinician)

‘Reminders to the patients is a good idea. However, we need to motivate the patients well. We send sheets to them asking to fill in the details of their blood sugar examination and diet. However, they do not follow.’ (Nurse)
DISCUSSION

The Chronic Care Model (CCM) is an established approach to diabetes management and is recommended by the American Diabetes Association. Multiple studies have shown the benefits of incorporating one or more components of CCM into diabetes care. Unfortunately, to our knowledge, there have been no efforts to incorporate CCM into diabetes care in low-income settings. By utilizing the Assessment of Chronic Illness Care and through in-depth interviews, we determined health providers’ perspectives on the opportunities and challenges for incorporating CCM into diabetes care in a community-based hospital in Nepal. The findings from this study provide insights for future directions of incorporating CCM in resource-limited settings.

We learned that hospital staff perceived that there is already basic support for the management of diabetes as a chronic illness at DH. The organization of health care system was found to be very favorable and supportive because of the leadership commitment to explore innovative approaches to diabetes care. The fact that the study site is a community-based, not-for-profit, tertiary level University hospital corresponds with these findings. In fact, it is one of the first institutions in Nepal to initiate dedicated nurse-led diabetes counseling center that works closely with the clinicians.

The willingness to test newer approaches to care, openness in partnering between departments and already existing robust clinical care with full tertiary level facilities were considered major opportunities for improving diabetes care. Furthermore, the unique network of rural community-based health facilities of Dhulikhel Hospital and a strong tie with the local community of Dhulikhel were considered as major opportunities for community linkages. Recently, DH had helped the formation of a local Diabetes Club with which it has been working closely in running community-based awareness and screening programs. Thus, there was a sense of overall optimism in further advancing community linkages.
Although the participants were confident that they could train diabetic inpatients (who spend a longer time in the hospital) in self-management, there were considerable doubts regarding the incorporation of self-management skills to the outpatients who had minimal time to spend at the hospital. Most of the outpatients come from rural areas using public transportation. They arrive late in the morning and need to leave early afternoon to catch public transportation to return home. After spending time in the registration, laboratory and the clinic, they have very little time to spare for the counseling sessions. Thus, they are not able to participate in long counseling sessions. Overall the participants believed that there were opportunities of redefining the delivery system design by organizing structured collaborations with other health professionals (e.g., nursing staff working in the wards, physiotherapists, surgeons, etc.) and training them. However, there were major concerns regarding the feasibility of clinical information system because of potential cost issues.

The challenges associated with the incorporation of the CCM mainly focused around three issues: lack of training of the providers in adopting this approach; resource constraints; and poor health literacy and difficulty for follow-up visits among the patients.

Historically, health systems were designed for acute care and the current method of training in health sciences is also largely focused on the acute-care approach. Management of chronic disease requires a fundamental shift in the approach to patient care as outlined in the components of CCM. It is thus indispensable to establish specific training and capacity-building opportunities for the health providers; and embed the concepts of chronic disease management in the training programs in health sciences. In our study, the nurse counsellors for diabetes patients were appreciated by all the interviewees and believed that they formed the vital part of diabetes care. However, there were concerns (by the nurses and the leadership) that there was a need of structured training for diabetes care providers; which should be further complemented by clarifying the roles, responsibilities, training opportunities and professional
growth of health professionals involved in diabetes care. This directly relates to the components of decision support and delivery system design. Nurse-run chronic disease clinics and team-based care involving physicians, nurses, and dieticians utilizing structured protocols have been successfully used in numerous diabetes programs in Ghana, South Africa, and Ethiopia.\textsuperscript{18-21} So far, Nepal does not have a dedicated training opportunities for diabetes care and there are no national level guidelines or patient management materials available for health providers. There is thus an urgent need to build national level protocols (if not at least institutional protocols), standard training materials and opportunities for professional advancement in diabetes care for health professionals.

Resource constraint is a common theme that emerges in almost all studies describing approaches to diabetes management.\textsuperscript{22} The components of CCM require substantial investments mainly in terms of engagement with the communities, instituting advanced health information technology for clinical information system, and communication with the patients. This is a greater challenge in low-income countries because of weak primary care systems.

Because patients are not tied to specific health service providers as in developed countries, it is difficult to gather patients from a particular community together to provide services and education. It is also common for patients to go from provider to provider in the private sector until they are satisfied with the care. Lack of a systematic referral mechanism and a robust medical information system further compounds the problem. The low number of human resources for health is another challenge leading to very minimal interaction opportunity between patients and the providers. These issues pose major challenges involving health providers in community-based programs. One of the ways to address this could be the integration of local community pharmacies, existing community health workers and lay health volunteers. There are several examples from Cameroon, Uganda, South Africa and Thailand
where they have mobilized non-professional peers to assist with diabetes case management and long-term self-care.23i

Regarding clinical information systems, there is a great need to find alternatives if advanced electronic health information technology is not feasible. Simple approaches of making a systematic record of patients, phone calls to those who are lost to follow-up, standard patient cards (similar in concept with the growth charts used for children), well-designed hand-written registries and scheduling tools would be helpful to implement prior to electronic records.

There are also examples from low-income settings where simple quality improvement techniques have proven to have outstanding results. A study on the assessment of the effect of audit on process of care indicators among patients in India revealed significant improvement in the quality of diabetes care in a primary care setting.24 It is especially relevant for our study because we found no systematic approach to assess the quality of care in DH. However, the participants expressed the desire to learn more about developing and implementing monitoring and evaluation tools.

Another major challenge we identified was the poor health literacy and difficulty for follow-up visits by the patients. It was clearly highlighted that most patients needed multiple sittings to understand details of diabetes and its management. However, it was very difficult since most lived in rural areas and it was logistically challenging for them to visit DH frequently. This was also another major challenge for training the patients on self-management. It is a common problem in most low-income settings where primary care in the local communities are virtually absent. This might be addressed by developing effective mass education programs, e.g., using radio and television announcements that will benefit people in these rural communities. It may also be relevant to develop culturally tailored educational materials that the patients can effectively use and understand even without the involvement of the health
service providers. Potential innovation in these areas could potentially provide mobile-phone based videos or audios that the patient (or family members) can play at their available times; developing effective patient education materials; and arranging of tele-consultations using simple phone calls.

**Study Limitations:** We are fully aware that this study is based on only one site and that study findings might not be generalizable. However, the community-based, not-for-profit nature of the institution closely resembles many government tertiary level hospitals where much of the context could be correlated. Another major limitation of the study was the inability to investigate the perspectives from the patients and their family members. While we agree that this is a major limitation, the perspectives from the providers also provide unique insights that can be complemented in future studies including patients and family members. The Assessment of Chronic Illness Care (version 3.5) is not a validated tool in the Nepalese setting. However, we believe that it is the most comprehensive and structured tool available for assessment of perceptions on chronic illness care in an institutional setting.
RECOMMENDATIONS

Based on the findings of the study, we have developed a set of feasible recommendations to incorporate the components of the CCM into diabetes care in Dhulikhel Hospital. These recommendations take into account the existing status of diabetes care in DH and also incorporate input from the study participants. We have divided the recommendations into those for leadership and for providers.

For Leadership:

1. Form an official multidisciplinary unit dedicated for chronic disease management.
2. Designate a person as chronic disease coordinator and assign him/her the task to facilitate improvement in the quality of chronic disease care including diabetes.
3. Mobilize academic leadership to incorporate the concepts of chronic disease management in the academic programs of the institution.
4. Allocate resources on high-return investments, mainly in capacity building (providing training for the diabetes nurses to be trainers; regular training for treating physicians), electronic health record system.
5. Facilitate linkages with potential funding agencies for investing on capacity building, human resource addition and infrastructure support for diabetes management.
6. Establish formal linkages with local community organizations and stakeholders in health (municipality, district health office, private health service providers) to collaborate with DH for advancing diabetes care.

For Providers:

1. Form a diabetes management group representing various disciplines within hospital.
2. Develop an institutional diabetes management protocol/guideline in consultation with other national and international experts.
3. Start simple audit mechanisms to regularly assess quality indicators which should include outcome (e.g., patient compliance, blood sugar control, etc.) as well as process indicators (e.g., average wait time, proportion of patients who didn’t participate in the counseling sessions, etc.)

4. Develop short training programs for other health providers in the hospital to take care of diabetes patients. This could include training of the in-patient nurses on diabetes counseling, training of rural health workers for the basic management of diabetes.

5. Collaborate with the Department of Community Programs to initiate community-level activities on diabetes awareness, screening and treatment.

6. Initiate less time consuming but sustainable community-level engagements by organizing training programs for local diabetes club, local pharmacies, and other local community organizations.

7. Mobilize health sciences students for organizing diabetes related trainings.

8. Partner with the Department of Pharmacy to initiate drug counseling programs.

9. Develop easy-to-use scheduling tools and patient cards (similar to growth card used in pediatrics) for easy assessment of the patients.

10. Initiate less costly interventions, e.g., phone calls to the patients lost to follow-up.

11. Develop and distribute flyers, web-based resources that patients can read or get access to outside regular hospital hours.
CONCLUSION

This study adds important information to the field of diabetes management in low-income settings. In a context where there is virtually no information on CCM usage for diabetes care, this study provides preliminary but critical insights into potential opportunities and challenges for incorporating the components of the CCM into diabetes care where resources are limited. It emphasizes that some of the local contexts in low-income settings may be too different to utilize experience gained in high-income settings. However, this study provides evidence that there are ample reasons to be hopeful about the implementation opportunities of CCM components into low-income settings as well. Recommendations based on data collected here provide feasible actions that may be taken at the leadership and provider level to improve diabetes care and management in Nepal. Many of these recommendations may be relevant to other low-income countries hoping to utilize the CCM for addressing the burden of diabetes and improving patient outcomes.
REFERENCES

ANNEX 1

Checklist for assessing the current status of diabetes care in Dhulikhel Hospital

Services offered for diabetes patients in the hospital:
Out-patient: Describe
In-patient: Describe
Laboratory facilities: Describe
Other specialties available: Describe

Number of doctors directly involved in diabetes care:
Number of nurses directly involved in diabetes care:
Other health providers directly involved in diabetes care:
Average number of new diabetes patients in the out-patient department:
Average number of old diabetes patients in the out-patient department:
Average number of diabetes patients in the in-patient department:
Counseling for diabetes patients: Describe
Health Records: Paper-based or electronic
ANNEX 2

Questionnaire for in-depth interview with DH leadership and the health providers

Unique Study ID:
Job title:
Date of interview:
Interviewer code:

Questions:
1. How do you describe the current diabetes care in Dhulikhel Hospital (DH)?
2. What do you think are the major strengths and weaknesses of the current diabetes care in DH?

After a brief orientation on Chronic Care Model

3. How relevant is the chronic care model in diabetes management in DH?
4. What do you think are the opportunities of incorporating the components of Chronic Care Model in diabetes management in DH?
5. What do you think are the challenges of incorporating the components of Chronic Care Model in diabetes management in DH?
DHULIKHEL HOSPITAL / UNIVERSITY OF WASHINGTON

CONSENT FORM

‘Health Providers’ Perspectives on Incorporating Chronic Care Model in the Management of Diabetes: Findings from a Community-based Hospital in Nepal’

In-depth interviews of the Dhulikhel Hospital leadership and health providers involved diabetes care

Dhulikhel Hospital and University of Washington
PI: Biraj M Karmacharya

Researchers’ statement
We are asking you to participate in this proposed research study. The purpose of this consent form is to give you the information you will need to help you decide whether to be in the study or not. Please read the form carefully. If you are not able to read yourself, you can choose anyone you trust to read for you. You may ask questions about the purpose of the research, what we would ask you to do, the possible risks and benefits, your rights as a volunteer, and anything else about the research that is not clear from this form. When we have answered all your questions, you can decide if you want to be in the study or not. This process is called “informed consent.” We will give you a copy of this form for your records.

PURPOSE OF THE STUDY
The purpose of the study is to understand the opportunities and challenge of incorporating the elements of Chronic Care Model (CCM) in diabetes care Dhulikhel Hospital Kathmandu University Hospital (DH).

STUDY PROCEDURES
Your participation will consist of an interview lasting not more than an hour. Questions will include your perspectives on the current modality of diabetes care in DH and your views on the opportunities and challenges of incorporating the components of Chronic Care Model in diabetes care in Dhulikhel Hospital. We will also administer a questionnaire that assesses your views on the current status of diabetes care in Dhulikhel Hospital. We will audio tape the interview and also make some notes during the interview. We will not take any video or pictures.

Please remember that your participation in this interview is completely voluntary. If there are certain questions you do not wish to answer, for any reason, please let the interviewer know you would like to
skip the question. If you would like to discontinue the interview in between and withdraw from the study, you can do that too. This will not in any way affect the way you are dealt/treated by the hospital staffs or the hospital leadership now or in future.

RISKS, STRESS, OR DISCOMFORT

We do not anticipate that you will experience any physical or mental distress while going through this interview process. One of the risks of participating in this study is that your personal information from the study materials might be released accidentally. We will take full precautions to avoid such incidents. However, in any case such incidents happen, we will inform you immediately and will try to address the situation to the best of our capacity.

If you ever feel that you are being harmed by the study, you can feel free to contact Dr. Biraj M Karmacharya (Phone: 977-9802000029) .who will do needful to clarify your doubts or arrange appropriate support for you. These services will be provided at no charge to you.

BENEFITS OF THE STUDY

There are no incentives available for participation in this study. However, the results of this study will be used to design better organization of diabetes care at DH. Thus, others might be benefitted in the long run.

CONFIDENTIALITY OF RESEARCH INFORMATION

We value the privacy of your personal information. The information you provide in this training/interview will be kept strictly confidential. We will remove any identifiers in the file names or documents associated with your training/interview. Your identifying information will not be published in any report, publication, presentation or reports without your consent. The study participants on whom the screening will be done, will also not be revealed what you had found during screening. They will be given reports based on the finding of the expert sonographer/cardiologists.

The informed consent forms will be kept in secured lockers in the Department of Community Programs of Dhusikhel Hospital. The key to this will be accessible to Dr. Biraj Karmacharya and his research assistant only. The audio files will not contain any identifiers but will still be stored in an encrypted folder in a password protected computer. Only the local PI will have access to that and will provide it to the study staff who will prepare a transcript out of it. The transcript of the audio file will not contain any identifying information. It will be used for data analysis.
OTHER INFORMATION
You may refuse to participate and you are free to withdraw from this study at any time without penalty or loss.

Subject’s statement
This study has been explained to me. I volunteer to take part in this research. I have had a chance to ask questions. If I have questions later about the research, or if I have been harmed by participating in this study, I can contact one of the researchers listed on the first page of this consent form. If I have questions about my rights as a research subject, I can call the Human Subjects Division at +1-206-543-0098. I will receive a copy of this consent form.

Copies to: Researcher
Subject
ANNEX 3

Assessment of Chronic Illness Care
Version 3.5

Please complete the following information about you and your organization. This information will not be disclosed to anyone besides the ICIC/TH team. We would like to get your phone number and e-mail address in the event that we need to contact you. All of the survey is voluntary and will be used for research purposes only. Please also indicate the names of persons (e.g., team members) who completed the survey with you. Later on in the survey, you will be asked to describe the process by which you complete the survey.

<table>
<thead>
<tr>
<th>Your name:</th>
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<tbody>
<tr>
<td>Study ID (Required):</td>
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<td>Month Day Year</td>
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<tr>
<th>Organization &amp; Address:</th>
<th>Names of other persons completing the survey with you</th>
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<td>1. NA</td>
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<td>3.</td>
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<tr>
<th>Your phone number:</th>
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| Your e-mail address: | Not Required |

Directions for Completing the Survey

This survey is designed to help systems and providers move toward the "state of the art" in managing chronic illness. The results can be used to help your team identify areas for improvement. Instructions are as follows:

1. **Answer each question** from the perspective of one physical site (e.g., a practice, clinic, hospital, health plan) that supports care for chronic illness.

   Please provide name and type of site (e.g., a practice, clinic, hospital, health plan).

2. **Answer each question** regarding how your organization is doing with respect to one disease or condition.

   Please specify condition.

3. For each row, **circle the point value** that best describes the level of care that currently exists in the site and condition you chose. The scale in this form presents key aspects of chronic illness care. Each aspect is divided into levels showing various stages in improving chronic illness care. The stages are represented by points that range from 0 to 11. The highest point values indicate that the actions described in that box are more fully implemented.

4. **Sum the points in each section** (e.g., total part 1 score), calculate the average score (e.g., total part 1 score / # of questions), and enter these scores in the space provided at the end of each section. Then sum all of the section scores and complete the average score for the program as a whole by dividing this by 6.

For more information about how to complete the survey, please contact:

Judith Schaefer, MPH
ingchronic Illness Care
A National Program of the Robert Wood Johnson Foundation
Group Health Cooperative of Puget Sound
1720 Minor Avenue, Suite 1290
Seattle, WA 98101-1448

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Assessment of Chronic Illness Care, Version 3.5

Part 1: Organization of the Healthcare Delivery System. Chronic illness management programs can be more effective if the overall system (organization) in which care is provided is oriented and led in a manner that allows for a focus on chronic illness care.

<table>
<thead>
<tr>
<th>Components</th>
<th>Level D</th>
<th>Level C</th>
<th>Level B</th>
<th>Level A</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall Organizational Leadership in Chronic Illness Care</td>
<td>does not exist or there is little interest</td>
<td>is reflected in value statements and business plans, but no resources are specifically earmarked to execute the work</td>
<td>is reflected by senior leadership and specific dedicated resources (dollars and personnel)</td>
<td>is part of the system’s long-term planning strategy, receives necessary resources, and specific people are held accountable</td>
</tr>
<tr>
<td>Score</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Organizational Goals for Chronic Care</td>
<td>do not exist or are limited to one or two issues</td>
<td>exist but are not actively reviewed</td>
<td>are measurable and reviewed</td>
<td>are measurable, reviewed regularly, and are incorporated into plan for improvement</td>
</tr>
<tr>
<td>Score</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Improvement Strategy for Chronic Illness Care</td>
<td>is ad hoc and not organized or supported consistently</td>
<td>utilizes ad hoc approaches for targeted problems as they emerge</td>
<td>utilizes a proven improvement strategy for targeted problems</td>
<td>includes a proven improvement strategy and is proactive in meeting organizational goals</td>
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<tr>
<td>Score</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Incentives and Regulations for Chronic Illness Care</td>
<td>are not used to influence clinical performance goals</td>
<td>are used to influence utilization and costs of chronic illness care</td>
<td>are used to support patient care goals</td>
<td>are used to motivate and empower providers to support patient care goals</td>
</tr>
<tr>
<td>Score</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Senior Leaders</td>
<td>encourage modification of the chronic care workforce</td>
<td>do not make improvements to chronic illness care a priority</td>
<td>encourage improvement efforts in chronic care</td>
<td>actively participate in improvement efforts in chronic care</td>
</tr>
<tr>
<td>Score</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Benefits</td>
<td>discourage patient self-management or system changes</td>
<td>neither encourage nor discourage patient self-management or system changes</td>
<td>encourage patient self-management or system changes</td>
<td>are specifically designed to promote better chronic illness care</td>
</tr>
<tr>
<td>Score</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td></td>
</tr>
</tbody>
</table>

Total Health Care Organization Score _________  Average Score (Health Care Org. Score / 6) _________

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### Part 2: Community Linkages

Linkages between the health delivery system (or provider practice) and community resources play important roles in the management of chronic illness.

<table>
<thead>
<tr>
<th>Components</th>
<th>Level D</th>
<th>Level C</th>
<th>Level B</th>
<th>Level A</th>
</tr>
</thead>
<tbody>
<tr>
<td>Linking Patients to Outside Resources</td>
<td>...is not done systematically.</td>
<td>...is limited to a list of identified community resources in an accessible format.</td>
<td>...is accomplished through a designated staff person or resource responsible for ensuring providers and patients make maximum use of community resources.</td>
<td>...is accomplished through active coordination between the health system, community service agencies and patients.</td>
</tr>
<tr>
<td>Score</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Partnerships with Community Organizations</td>
<td>...do not exist.</td>
<td>...are being considered but have not yet been implemented.</td>
<td>...are formed to develop supportive programs and policies.</td>
<td>...are actively sought to develop formal supportive programs and policies across the entire system.</td>
</tr>
<tr>
<td>Score</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Regional Health Plans</td>
<td>...do not coordinate chronic illness guidelines, measures or care resources at the practice level.</td>
<td>...would consider some degree of coordination of guidelines, measures or care resources at the practice level but have not yet implemented changes.</td>
<td>...currently coordinate guidelines, measures or care resources at the practice level.</td>
<td>...currently coordinate chronic illness guidelines, measures and resources at the practice level for most chronic illnesses.</td>
</tr>
<tr>
<td>Score</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

**Total Community Linkages Score** __________  
**Average Score (Community Linkages Score / 3)** __________
**Part 3: Practice Level.** Several components that manifest themselves at the level of the individual provider practice (e.g., individual clinic) have been shown to improve chronic illness care. These characteristics fall into general areas of self-management support, delivery system design issues that directly affect the practice, decision support, and clinical information systems.

**Part 3a: Self-Management Support.** Effective self-management support can help patients and families cope with the challenges of living with and treating chronic illness and reduce complications and symptoms.

<table>
<thead>
<tr>
<th>Components</th>
<th>Level D</th>
<th>Level C</th>
<th>Level B</th>
<th>Level A</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assessment and Documentation of Self-Management Needs and Activities Score</td>
<td>... are not done</td>
<td>... are expected</td>
<td>... are completed in a standardized manner</td>
<td>... are regularly assessed and recorded in standardized form linked to a treatment plan available to practice and patients</td>
</tr>
<tr>
<td>Self-Management Support Score</td>
<td>... is limited to the distribution of information (pamphlets, brochures)</td>
<td>... is available by referral to self-management classes or educators</td>
<td>... is provided by trained clinical educators who are designated to do self-management support, affiliated with each practice, and see patients in referral</td>
<td>... is provided by clinical educators affiliated with each practice, trained in patient empowerment and problem-solving methodologies, and see most patients with chronic illness</td>
</tr>
<tr>
<td>Addressing Concerns of Patients and Families Score</td>
<td>... is not consistently done</td>
<td>... is provided for specific patients and families through referral</td>
<td>... is encouraged, and peer support, groups, and monitoring programs are available</td>
<td>... is an integral part of care and includes systematic assessment and routine involvement in peer support, groups or monitoring programs</td>
</tr>
<tr>
<td>Effective Behavior Change Interventions and Peer Support Score</td>
<td>... are not available</td>
<td>... are limited to the distribution of pamphlets, brochures or other written information</td>
<td>... are available only by referral to specialized centers staffed by trained personnel</td>
<td>... are readily available and an integral part of routine care</td>
</tr>
</tbody>
</table>

Total Self-Management Score: Average Score (Self-Management Score / 4):

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### Part 3b: Decision Support

Effective chronic illness management programs assure that providers have access to evidence-based information necessary to care for patients—decision support. This includes evidence-based practice guidelines or protocols, specialty consultation, provider education, and activating patients to make provider teams aware of effective therapies.

<table>
<thead>
<tr>
<th>Components</th>
<th>Level D</th>
<th>Level C</th>
<th>Level B</th>
<th>Level A</th>
</tr>
</thead>
<tbody>
<tr>
<td>Evidence-Based Guidelines</td>
<td>0</td>
<td>1, 2</td>
<td>3, 4, 5</td>
<td>6, 7, 8, 11</td>
</tr>
<tr>
<td>Score</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Involvement of Specialists in</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Improving Primary Care</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Score</td>
<td>0, 1, 2</td>
<td>3, 4, 5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Provider Education for Chronic</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Illness Care</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Score</td>
<td>0, 1, 2</td>
<td>3, 4, 5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Informing Patients about</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Guidelines</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Score</td>
<td>0, 1, 2</td>
<td>3, 4, 5</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Total Decision Support Score       Average Score (Decision Support Score / 4)
### Part 3c: Delivery System Design

Evidence suggests that effective chronic illness management involves more than simply adding additional interventions to a current system focused on acute care. It may necessitate changes to the organization of practice that impact provision of care.

<table>
<thead>
<tr>
<th>Components</th>
<th>Level D</th>
<th>Level C</th>
<th>Level B</th>
<th>Level A</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Practice Team Functioning</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Practice Leadership</td>
<td>is not recognized locally or by the system</td>
<td>is assumed by the organization to evolve in specific organizational rules</td>
<td>is assumed by the appointment of a team leader but whose role in chronic illness is not defined</td>
<td>is assumed by teams who meet regularly and have clearly defined roles including patient care management education, preventive follow-up, and resource coordination and other skills in chronic illness care</td>
</tr>
<tr>
<td>Score</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td><strong>Appointments System</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>can be used to schedule acute care visits, follow-up and preventive visits</td>
<td>assumes scheduled follow-up with chronically ill patients</td>
<td>are flexible and can accommodate innovations such as customized visit length or group visits</td>
<td>includes organization of care that facilitates the patient seeing multiple providers in a single visit</td>
<td></td>
</tr>
<tr>
<td>Score</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td><strong>Follow-up</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>is scheduled by patients or providers in an ad hoc fashion</td>
<td>is scheduled by the practice in accordance with guidelines</td>
<td>is assumed by the practice team by monitoring patient utilization</td>
<td>is customized to patient needs, varies in intensity and methodology (phone, in-person, email) and ensures guideline follow-up</td>
<td></td>
</tr>
<tr>
<td>Score</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td><strong>Fluency Visits for Chronic Illness Care</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>are not used</td>
<td>are occasionally used for complicated patients</td>
<td>are an option for interested patients</td>
<td>are used for all patients and include regular assessment, preventive interventions and attention to self-management support</td>
<td></td>
</tr>
<tr>
<td>Score</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td><strong>Continuity of Care</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>is not a priority</td>
<td>depends on written communication between primary care providers and specialists, case managers or disease management</td>
<td>between primary care providers and specialists and other relevant providers is a priority but not implemented systematically</td>
<td>is a high priority and all chronic disease interventions include active coordination between primary care, specialists and other relevant providers</td>
<td></td>
</tr>
</tbody>
</table>

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<table>
<thead>
<tr>
<th>Components</th>
<th>Level D</th>
<th>Level C</th>
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<th>Level A</th>
</tr>
</thead>
<tbody>
<tr>
<td>Score</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td></td>
</tr>
</tbody>
</table>

(From Previous Page)

Total Delivery System Design Score

Average Score (Delivery System Design Score / 6)

Part 3.4: Clinical Information Systems. Timely, useful information about individual patients and populations of patients with chronic conditions is a critical feature of effective programs, especially those that employ population-based approaches.5

<table>
<thead>
<tr>
<th>Components</th>
<th>Level D</th>
<th>Level C</th>
<th>Level B</th>
<th>Level A</th>
</tr>
</thead>
<tbody>
<tr>
<td>Registry (list of patients with specific conditions)</td>
<td>is not available</td>
<td>includes name, diagnosis, contact information and date of last contact either on paper or in a computer database</td>
<td>allows queries to sub-populations by clinicians</td>
<td>is tied to guidelines which provide prompts and reminders about needed services</td>
</tr>
<tr>
<td>Score</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td></td>
</tr>
</tbody>
</table>

Reminders to Providers

| Score                                          | 0       | 1       | 2       |         |

Feedback

| Score                                          | 0       | 1       | 2       |         |

Information about Relevant Subgroups of Patients Needing Services

| Score                                          | 0       | 1       | 2       |         |

Patient Treatment Plans

| Score                                          | 0       | 1       | 2       |         |

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Total Clinical Information System Score:  
Average Score (Clinical Information System Score / 5): 

**Integration of Chronic Care Model Components.** Effective systems of care integrate and combine all elements of the Chronic Care Model, e.g., linking patients’ self-management goals to information systems/registries.

<table>
<thead>
<tr>
<th>Components</th>
<th>Little support</th>
<th>Basic support</th>
<th>Good support</th>
<th>Full support</th>
</tr>
</thead>
<tbody>
<tr>
<td>Informed Patients about Guidelines</td>
<td>...is not done</td>
<td>...happens on request or through system publications.</td>
<td>...is done through specific patient education materials for each guideline.</td>
<td>...includes specific materials developed by persons which describe their role in achieving guideline adherence.</td>
</tr>
<tr>
<td>Score</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3 4 5</td>
</tr>
<tr>
<td>Information System/Registries</td>
<td>...do not include self-management goals.</td>
<td>...include results of patient assessments (e.g., functional status, capacity to engage in self-management activities), but no goals.</td>
<td>...include results of patient assessments, as well as self-management goals that are developed using input from the practice team and patient, and prompt revision to the plan and for providers about following and provide re-evaluation targets.</td>
<td>...include results of patient assessments, as well as self-management goals that are developed using input from the practice team and patient, and prompt revision to the plan and for providers about following and provide re-evaluation targets.</td>
</tr>
<tr>
<td>Score</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3 4 5</td>
</tr>
<tr>
<td>Community Programs</td>
<td>...do not provide feedback to the health care system about patients’ progress in their programs</td>
<td>...provide feedback to the health care system about patients’ progress in their programs</td>
<td>...provide regular feedback to the health care system about patients’ progress that requires input from patients that is then used to modify programs to better meet the needs of patients.</td>
<td>...provide regular feedback to the health care system about patients’ progress that requires input from patients that is then used to modify programs to better meet the needs of patients.</td>
</tr>
<tr>
<td>Score</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3 4 5</td>
</tr>
<tr>
<td>Organizational Planning for Chronic Home Care</td>
<td>...does not involve a population-based approach.</td>
<td>...uses data from information systems to plan care.</td>
<td>...uses data from information systems to proactively plan population-based care, including the development of self-management programs and partnerships with community resources.</td>
<td>...uses systematic data and input from practice teams to proactively plan population-based care, including the development of self-management programs and community partnerships that include a built-in evaluation plan to determine success over time.</td>
</tr>
<tr>
<td>Score</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3 4 5</td>
</tr>
<tr>
<td>Component</td>
<td>Limited support</td>
<td>Basic support</td>
<td>Good support</td>
<td>Full support</td>
</tr>
<tr>
<td>-----------------------------------------------</td>
<td>--------------------------------------------------------------------------------</td>
<td>--------------------------------------------------------------------------------</td>
<td>--------------------------------------------------------------------------------</td>
<td>--------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Routine follow-up for appointments, patient assessments and goal planning</td>
<td>... is not ensured.</td>
<td>... is specifically done, usually for appointments only.</td>
<td>... is ensured by assigning responsibilities to specific staff (e.g., nurse case manager), who use the registry and other prompts to coordinate with patients and the entire practice team.</td>
<td></td>
</tr>
<tr>
<td>Guidelines for chronic illness care</td>
<td>... are not shared with patients.</td>
<td>... are given to patients who express a specific interest in self-management of their condition.</td>
<td>... are provided for all patients to help them develop effective self-management of behaviors, communication programs, and identify when they should see a provider.</td>
<td>... are reviewed by the practice team with the patient to devise a self-management of behaviors modification program consistent with the guidelines that takes into account patient’s goals and readiness to change.</td>
</tr>
</tbody>
</table>

Total Integration Score (SUM items): ________  ➤  Average Score (Integration Score/6) = ________

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Briefly describe the process you used to fill out the form (e.g., reached consensus in a face-to-face meeting; filled out by the team leader in consultation with other team members as needed; each team member filled out a separate form and the responses were averaged).

Description: ____________________________________________

__________________________________________________________________________

Scoring Summary

(bring forward scoring at end of each section to this page)

Total Org. of Health Care System Score
Total Community Linkages Score
Total Self-Management Score
Total Decision Support Score
Total Delivery System Design Score
Total Clinical Information System Score
Total Integration Score

Overall Total Program Score (Sum of all scores)

Average Program Score (Total Program /?)

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What does it mean?

The ACIC is organized such that the highest “score” (an “11”) on any individual item, subscale, or the overall score (an average of the six ACIC subscale scores) indicates optimal support for chronic illness. The lowest possible score on any given item or subscale is a “0”, which corresponds to limited support for chronic illness care. The interpretation guidelines are as follows:

Between “0” and “2” = limited support for chronic illness care  
Between “3” and “5” = basic support for chronic illness care  
Between “6” and “8” = reasonably good support for chronic illness care  
Between “9” and “11” = fully developed chronic illness care

It is fairly typical for teams to begin a collaborative with average scores below “5” on some (or all) areas of the ACIC. After all, if everyone was providing optimal care for chronic illness, there would be no need for a chronic illness collaborative or other quality improvement programs. It is also common for teams to initially believe they are providing better care for chronic illness than they actually are. As you progress in the Collaborative, you will become more familiar with what an effective system of care involves. You may even notice your ACIC scores “declining” even though you have made improvements; this is most likely the result of your better understanding of what a good system of care looks like. Over time, as your understanding of good care increases and you continue to implement effective practice changes, you should see overall improvement on your ACIC scores.
ANNEX 4

Handout on Chronic Care Model

Based on the information from the following website:
[Copyright: 2006-2017 Improving Chronic Illness Care, Group Health Research Institute]

The Chronic Care Model
The Chronic Care Model (CCM) is an organizational approach to caring for people with chronic
disease in a primary care setting. The system is population-based and creates practical,
supportive, evidence-based interactions between an informed, activated patient and a
prepared, proactive practice team.

The CCM identifies essential elements of a health care system that encourage high-quality
chronic disease care: the community; the health system; self-management support; delivery
system design; decision support, and clinical information systems. Within each of these
elements, there are specific concepts (“Change Concepts”) that teams use to direct their
improvement efforts. Change concepts are the principles by which care redesign processes
are guided.

The items below are the change concepts associated with each component of the model that,
when implemented, result in improved patient and system outcomes.

Health Systems
Create an organization that provides safe, high quality care
A health system’s business plan reflects its commitment to apply the CCM across the
organization. Clinician leaders are visible, dedicated members of the team.

- Visibly support improvement at all levels of the organization, beginning with the senior
  leader
- Promote effective improvement strategies aimed at comprehensive system change
- Encourage open and systematic handling of errors and quality problems to improve care
- Provide incentives based on quality of care
- Develop agreements that facilitate care coordination within and across organizations

The Community
Mobilize community resources to meet needs of patients
Community resources, from school to government, non-profits and faith-based organization, bolster health systems’ efforts to keep chronically ill patients supported, involved and active.

- Encourage patients to participate in effective community programs
- Form partnerships with community organizations to support and develop interventions that fill gaps in needed services
- Advocate for policies that improve patient care

Self-Management Support
Empower and prepare patients to manage their health care
Patients are encouraged to set goals, identify barriers and challenges, and monitor their own conditions. A variety of tools and resources provide patients with visual reminders to manage their health.

- Emphasize the patient’s central role in managing his or her health
- Use effective self-management support strategies that include assessment (physician or self?), goal-setting, action planning, problem-solving and follow-up
- Organize internal and community resources to provide ongoing self-management support to patients

Delivery System Design
Assure effective, efficient care and self-management support
Regular, proactive planned visits which incorporate patient goals help individuals maintain optimal health, and allow health systems to better manage their resources. Visits often employ the skills of several team members.

- Define roles and distribute tasks among team members
- Use planned interactions to support evidence-based care
- Provide clinical case management services for complex patients
- Ensure regular follow-up by the care team
- Give care that patients understand and that agrees with their cultural background

Decision Support
Promote care consistent with scientific data and patient preferences
Clinicians have convenient access to the latest evidence-based guidelines for care for each chronic condition. Continual educational outreach to clinicians reinforces utilization of these standards.

- Embed evidence-based guidelines into daily clinical practice
- Share evidence-based guidelines and information with patients to encourage their participation
- Use proven provider education methods
- Integrate specialist expertise and primary care

Clinical Information Systems
Organize data to facilitate efficient and effective care
Health systems harness technology to provide clinicians with an inclusive list (registry) of patients with a given chronic disease. A registry provides the information necessary to monitor patient health status and reduce complications.

- Provide timely reminders for providers and patients
- Identify relevant subpopulations for proactive care
- Facilitate individual patient care planning
- Share information with patients and providers to coordinate care
- Monitor performance of practice team and care system