ENVIRONMENTAL SCAN: CHRONIC DISEASE PREVENTION AND MANAGEMENT FOR THE NORTH WEST LHIN

Research Team

Bruce Minore, Mary Ellen Hill, Serenity Perry

Centre for Rural and Northern Health Research

Lakehead University

Thunder Bay, Ontario

Report submitted to the North West LHIN

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For further information, please contact:

Dr. Mary Ellen Hill
The Centre for Rural and Northern Health Research
Lakehead University, 955 Oliver Road
Thunder Bay, Ontario, Canada
P7B 5E1
Telephone: (807) 766-7278
Email: maryellen.hill@lakeheadu.ca

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EXECUTIVE SUMMARY

INTRODUCTION

Cancer, cardiovascular disease (CVD), respiratory illnesses, and diabetes are the major non-communicable chronic diseases in Canada.[1] In 2007, a survey by the Health Council of Canada reported that over 10 million Canadian adults and 68% of seniors have one or more chronic health conditions.[2] The social, economic and personal costs of chronic diseases are significant; chronic conditions are the leading causes of avoidable illness, death and disability worldwide and account for a substantial proportion of the health care system utilization.[3]

This report responds to the North West LHIN's interest in conducting a literature review and environmental scan on chronic disease as the basis for enhancing chronic disease management strategies in Northwestern Ontario. Taking an approach similar to that used by the Ontario Chronic Disease Prevention Alliance and Public Health Association in their scan of chronic disease prevention approaches,[4] the study explores chronic disease management models and prevention initiatives implemented in Canada and other jurisdictions, with a focus on factors facilitating or impeding the development of integrated care models. As a basis for enhancing chronic disease management and prevention initiatives in the NW LHIN, it also documents the experiences and opinions of Northwestern Ontario health care administrators and front-line providers who are actively involved in delivering chronic disease programs throughout the region.

Research Questions

Using quantitative and qualitative methods, the study explored four primary research questions:

1. What are the prevalence rates of chronic disease particularly in relation to individuals who reside in remote and rural regions of Northwestern Ontario (particularly in regards to incidence of chronic disease occurring in NW Ontario First Nation communities)?
2. What types of chronic disease management and prevention initiatives have been implemented in NW Ontario, in terms of their structure, implementation strategies and outcomes related to health initiatives and programming?
3. What types of chronic disease management frameworks have been implemented in other regions of Canada and other countries, to enhance integration of chronic disease management and prevention initiatives?
4. What are the lessons learned, regarding the factors which facilitate or impede development of chronic disease management and prevention initiatives in rural or northern regions, that might be applied to the NW LHIN?

Methods

The review synthesized knowledge from three sources: a comprehensive scan of the published literature, a statistical analysis, and key informant interviews conducted with health care service providers in Northwestern Ontario communities. With these objectives in mind, the primary research tasks were to:

1. Review literature on chronic disease management frameworks to identify factors which may contribute to the successful development and implementation of a chronic disease management plan.
2. Describe socioeconomic, demographic and health status indicators using available statistical databases, with a focus on chronic disease and risk factors, in urban, rural and remote Northwestern Ontario communities.

3. Explore available information on the status of chronic disease management and prevention initiatives in Northwestern Ontario communities and examine the implementation and success rates of existing chronic disease intervention programs.
4. Conduct key informant interviews with health care providers to provide further insights into chronic illness management and prevention in Northwestern Ontario communities.
5. Summarize the evidence regarding the data gathered from research conducted on the subject of chronic disease management and prevention in Northwestern Ontario.

Literature Review and Data Sources

The review identified published literature, both health sector and non-health sector, national and international using the following electronic database search engines: PubMed, CINAHL, PsycINFO, Sociofile, Teoma, Google Scholar, and INFOMINE. Web-searches of key government and non-governmental organizations were enlisted to help identify the so-called grey literature – reports, policy and position papers, and non-scientific articles.

To obtain LHINS-specific chronic disease data, the research team examined data from two sources: the Health System Intelligence Project Report on Chronic Conditions in the North West LHIN[5] and the Institute for Clinical Evaluative Sciences (ICES) on-line Intool.[6] Comparable Ontario and Canadian data, including information specific to Aboriginal peoples, was located in published articles and reports from provincial and federal departments and health care organizations.

Northwestern Ontario Key Informant Interviews

To explore chronic disease management challenges and opportunities, open-ended interviews (Appendix A) were completed with 18 health care administrators and front-line professionals representing family health teams, health centres, hospitals, and voluntary organizations across the region.[7] [8] Initial informants were identified by the NWLHIN staff and additional respondents located through snowball sampling.

All procedures for the study were approved by the Research Ethics Boards of Lakehead University and St. Joseph's Care Group.[9] Confidentiality of quantitative statistical data assured by aggregating at a level that protects individual confidentiality. For the qualitative portion, interviewees were assured in covering letter and consent forms (Appendices B and C) that answers were confidential and they would not be identified in any written report or subsequent presentation of results.

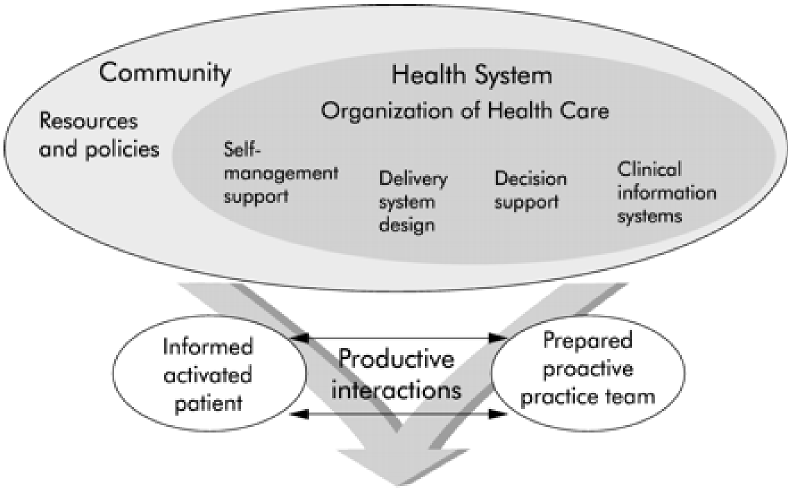
This Report

Information from the study's literature review, together with the statistical analysis and interview data, was synthesized into this report. It summarizes findings, conclusions, and gaps in knowledge, as well as policy implications. At the discretion of the North West LHIN, findings will be disseminated through stakeholder and conference presentations, publications and web postings.

THE CHRONIC DISEASE MANAGEMENT MODEL

The Chronic Disease Management Model offers six different types of support to promote effective healthcare delivery: organizational support, clinical informational systems, delivery system design, decision support, self-management support and community resources. Chronic disease management or practice improvement can be based on each of the concepts separately or on the model as a whole.

Figure 1: The Chronic Care Model (Adapted from Wagner, 1998) [10]



Organizational Support

Organizational support is a concept which examines both the culture of practice and system leadership. The ideal practice has a culture where the optimal management of chronic illness and practice improvement are integral to the foundation of the model. Leadership play an integral role in the successful implementation of the chronic care model, ideally, leadership is committed and involved, supports change and quality improvement and creates incentives for providers and patients to improve care and adhere to evidence-based practice.[11] The role of practice leaders is to establish program expectations, ensure that the quality of care is a priority and provide the resources necessary to support the implementation and provision chronic care.

Clinical Information Systems

Improving medical and chronic care practices is not possible without access to individual patient data. Clinical information systems (CIS) are structured to organize patient, population and provider data to describe the health of the population and facilitate efficient and effective care. The clinical information system should include a disease registry and provider-specific performance guidelines. It may also include a registry to document patient-specific needs and reminder systems to generate tailored treatment planning forms, encounter forms and client or provider messages. A number of studies suggest that such systems improve care process.[12] [13]

Delivery System Design

The delivery system design component of the Chronic Care Model addresses issues regarding the practice team, the organization of visits and the management of follow-up care. The delivery of effective, efficient clinical care through appropriate use of all team members, planned patient interactions, regular follow-up, and case-management are all integral parts of the delivery system design component.[14] Recommended improvements include "group visits," in which clients have time allocated with their primary care provider and with specialized allied health professionals, such as physiotherapists, occupational therapists, psychologists or health educators. This modification in the delivery system has been shown to improve outcomes and increase patient satisfaction with the care provided.[15]

Decision Support

The role of evidence-based practice guidelines is to provide standards for care, such standards should be available in daily practice, as should the integration of clinical expertise from specialists and generalists. Research into chronic disease management reveals that increasing provider access to evidence-based practice guidelines and to specialists for collaboration, along with system prompts and reminders, produce improvements in the process of care delivery.[16] [17] [18]

Self-Management Support

Self-Management has been defined as "the ability of the patient to deal with all that a chronic illness entails, including symptoms, treatment, physical and social consequences and lifestyle changes."[19] Physician support of patient self-management is one of the key elements of a systems oriented chronic care model. Increasing evidence indicates that self management support reduces hospitalizations, emergency department use and overall care costs, although there is little evidence available regarding the cost of self-management interventions in individual non-managed care practices.[20]

INTEGRATED MANAGEMENT AND PREVENTION MODELS

(1) Kaiser Permanente Integrated Management Model (United States)

In the healthcare sector, one example of a fully integrated system is provided by Kaiser Permanente, a health maintenance organization in the United States. Goodwin et al. (2004) identified a series of key attributes that characterize integrated delivery systems such as that of Kaiser Permanente, including: a population defined by enrolment, contractual responsibility for a defined package of comprehensive healthcare services, financing on the basis of pooling multiple funding streams, a closed network (i.e. a selected group of contracted or salaried providers), emphasis on primary care and non-institutional services, use of micromanagement techniques to ensure appropriate quality of care and to control costs (e.g. utilization review, disease management) and multidisciplinary teams working across the network with joint clinical responsibility for outcomes.[21]

The initial focus of the Kaiser Permanente model was on the care and case management of high-risk patients[22]but it has gradually expanded to include the entire population with chronic disorders at all three levels of healthcare "need". The organisation also uses 'population wide prevention' and 'risk stratification' as phrases to convey broader health promotion in the community and for identifying clients at risk.

Kaiser Permanente Triangle of Care

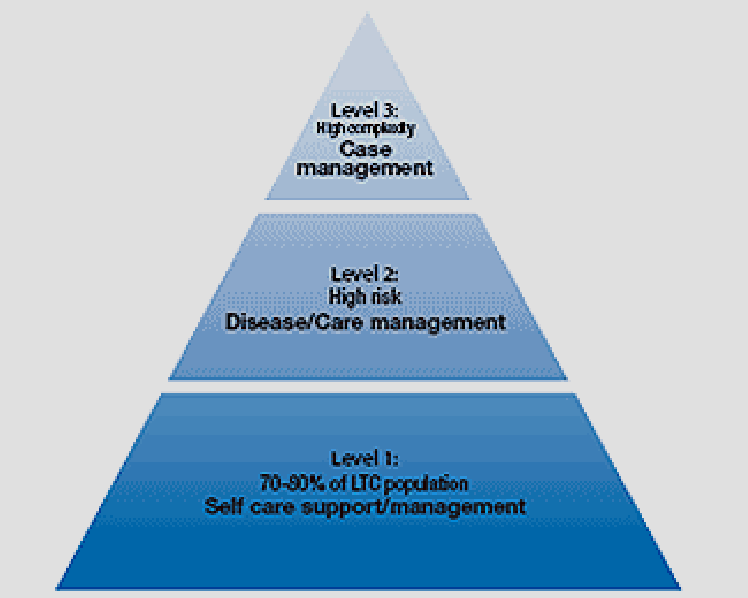


Figure 1 – Kaiser Permanente Triangle of Care

A key feature of the approach taken by Kaiser Permanente to chronic care is the application of a population management model (known as the Kaiser Permanente Triangle or Pyramid of Care) [23] that divides the population of patients with chronic conditions into three distinct groups based on their degree of need:

i. Relatively low level of need for healthcare: their chronic condition is reasonably under control, with support for self management of their condition provided through the primary care team. This population constitutes the majority of the population with chronic conditions.

ii. Increased risk because their condition is unstable, or because, in some cases their conditions are likely to deteriorate, unless they have structured support through specialist disease management.

iii. Highly complex needs and/or high intensity use of unplanned secondary care (i.e. emergency admissions) who require active management through case managers.

The ‘Kaiser Permanente Pyramid’ has proved to be an influential and useful method for conceptualising risk stratified groups of patients with long term conditions and the appropriate level of management. The Kaiser chronic care model describes ‘case management’ at the top of the pyramid as the central requirement for individuals with complex chronic care needs and high health care resource use, whereby a case manager assists them in navigating the service sector and provides support via the telephone. At the next level, ‘case-management’ provides for high-risk individuals primarily using group education. ‘Supported self management’ is the level of care for individuals with good control of their health, and routine medical review is provided.

(2) Stanford Chronic Disease Self-Management Programs (United States)

A common barrier to successful implementation of chronic disease management is the fact that chronic conditions often occur as co-morbidities. As reported in an survey by the Robert Wood Johnston Foundation, older persons with complex chronic conditions may be seen by as many as eight different physicians during an average year.[24] They also require care on a regular basis from multiple professionals in the health and social care fields in order to manage their condition.[25] During the transition from one health care setting to another or from one health care professional to another, aggravation of one condition by the symptoms or treatment of another and problems created by multiple medication regimens can occur[26] and the quality of care can suffer.[27] There are, however, several examples of innovative self-management programs designed to address these issues.

The Chronic Disease Self-Management Program (CDSMP) developed at Stanford, recognises that people with chronic illness deal with issues such as pain management, stress and the need to develop coping mechanisms on a daily basis. The CDSMP course is led by teams of trained volunteers all living with a chronic illness. Three principal assumptions underlie the CDSMP: (1) patients with different chronic diseases have similar self-management problems and disease-related tasks; (2) patients can learn to take responsibility for the day-to-day management of their diseases; and (3) confident, knowledgeable patients practicing self-management will experience improved health status and will utilize fewer health care resources.[28] Recent evaluative studies confirm improved health status, enhanced health behaviours, and decreased health care utilization in patients who participated in the CDSMP program.[29] Though it was designed in the U.S., the Stanford Program has spread throughout the world.

(3) Expert Patients Program (Britain)

The Expert Patients Program (EPP) was launched by the Department of Health in England in 2001 to improve self care. The Expert Patients Program is a six-week skills course, which is organised and delivered through Primary Care Trusts (PCTs) by volunteer tutors who have personal experience of living with a chronic condition. The course is open to anyone with a self-defined long-term condition and involves weekly 2.5 hour group sessions.

A randomised controlled trial [30] confirmed that the course increased patients' self-efficacy by a moderate amount and reduced costs of services overall because of declines in overnight hospital stays and use of day care. [31] A number of barriers to success, however, were identified. Difficulties fitting the program into existing primary and secondary care, engaging health professionals, recruiting people from ethnic groups or disadvantaged areas, [32] and managing volunteers, [33] were reported. Course content also failed to address socio-economic issues, such as benefits for people who are unable to work or who need assistance in returning to work.[34]

(4) PRIISME (50 Projects Across Canada)

PRIISME, a public-private partnership, provides an integrated approach to managing chronic disease. The PRIISME goal is to empower people who suffer from asthma, diabetes and chronic obstructive pulmonary disease (COPD) to participate in achieving their full potential for health. Since its launch in 1999, PRIISME has implemented more than 50 projects in Canada with concrete results, including a significant decrease of 30 to 40% in visits to hospital emergency rooms and hospitalizations, as well as a significant reduction in work absenteeism rates.[35] The concept is a multi-disciplinary primary care model that involves physicians and allied health professionals that encourages patient self-management.

Evaluations by the Change Foundation[36] show patients' knowledge of their conditions and self-management skills improved. Their awareness of chronic disease and of the resources available to improve symptom control increased. The greatest impact for health-care providers was improved patient care, specifically the support of self-care, and knowledge of evidence-based guidelines. Project assessments documented that patients exhibited improved health outcomes, were more likely to use education services, and generally better quality of life.

(5) Chronic Disease Management Collaborative (Saskatchewan)

In November 2005, Saskatchewan embarked upon a large healthcare quality improvement initiative. The Saskatchewan Chronic Disease Management (CDM) Collaborative, sponsored by the province's Health Quality Council, was founded as a means by which to improve the quality of care and the health status of people living with chronic disease, in particular, those with coronary artery disease (CAD) and diabetes in Saskatchewan, as well as to improve access to physician practices. The collaborative involves 28 percent of the province's family physicians and about 30 percent of its primary care practices; more than 600 health professionals; all 13 of Saskatchewan's health regions; and more than 15,000 people living with diabetes and coronary artery disease.[37]

The collaborative employs a Chronic Disease Management Toolkit, used by doctors, authorized office staff and health care providers as a web-based electronic patient registry and decision support tool. The Toolkit tracks a patient's care and reminds care providers of required tests, services or medications. With evidence-based flow sheets at the hub of this application, providers can more effectively manage their CDM patients both at an individual and population level and track their improvements in care.

The toolkit enables all providers involved in the care of the same patient to share information with each other and facilitates coordination of care.[38] In two years, there have been notable improvements across many key measures from baseline, including improvements in screening, prescribing patterns and rehabilitation referrals.

(6) Cote-des-neiges Diabetes Program (Montreal, Quebec)

The Côte-des –Neiges area of Montreal is the second most-populated area within the province of Quebec (130,448 inhabitants in 2000). Significant variations in socioeconomic status exist among the 127 different ethnic groups, and certain communities within the Côte-des-Neiges area represent the poorest in the city of Montreal. The Côte-des-neiges- health care system is composed of 12 medical clinics, more than 50 practitioners' offices, three acute care hospitals, and one CLSC.[39] It is estimated that there are 15,000 individuals with diabetes, of which only half have been diagnosed, within the area and, until this initiative, had received most services from family physicians. Other services, such as nutrition counselling or footcare, were only accessible through waist-lists, that were several months long. [40]

The Cote-des-neiges Diabetes Initiative involved a needs assessment and resource inventory, an interdisciplinary team to support evaluations and multilingual educational services (coordinator, two nurses, dietician, foot care technician, community organizer, social worker, and exercise consultant) and practice supports (computer, software, flowcharts, referral sheets, CME and CD-roms on current practice guidelines).

Evaluations confirmed that both physicians and patients perceived the benefit of having access to services that otherwise were not available. Physicians, however, found the computer system too time-consuming to integrate into their daily practice and did not use the software or CD-rom resources, preferring to manage clients using hard-copy flow charts and referral sheets.

(7) Latin American Diabetes Program (London, Ontario)

The Latin American Diabetes Program (LADP) was established by the London Intercommunity Health Centre (LIHC) in 1999 and is an example of an integrated systems approach to chronic disease prevention and management (CDPM) in practice. Latinos represented 5% (20,000) of London's population, with a 10% incidence rate and a 40% lifetime prevalence rate for diabetes, nearly four times the rates for Canadians in general.[41] [42] Existing diabetes programs were difficult to access and failed to take into account the determinants of health for Latinos.[43] [44]

The program uses a point of care primary health care approach that is also centered on the client and covers the spectrum from health promotion and primary prevention through management of the disease, with services provided on a one-to-one basis by an interdisciplinary team consisting of a nurse practitioner, dietician, and foot nurse. It also uses risk stratification to identify appropriate care-paths, sending clients into either the primary prevention or complication prevention stream,[45] using software to track client outcomes, clinical case management, and planning follow-up.[46]

Client services and resource materials are culturally and linguistically appropriate. Other supports are provided to participating families, including family-centered programming, fruit and vegetable vouchers, interpreters, paid YMCA memberships for families with obese children and English as a second language classes.

(8) MicoHealth Internet Diabetes Program (Kitchener, Ontario)

The MicoHealth Internet Diabetes Management Program offers an online diabetes management program which provides access to a range of educational, planning, data collection graphing, and communication tools to promote improved self-management of diabetes. The objectives include improving glycemic control, disease management behaviours, health status and patient satisfaction. Two clinical trials of the program both showed positive results.[47]

The internet program consisted of a central data repository that the patient or healthcare provider could access via a confidential password. Patients were able to enter data on blood glucose measurements, diet, exercise, insulin and oral medications. A diabetes nurse, working under medical directives, had access to all patient profiles and was able to monitor data, give feedback, make recommendations about treatment and provide individualized patient education.

The program also included a chatting or communication module, which enabled patient-to-patient discussions and bulletin boards, which allowed patients to post questions and helpful information on managing lifestyle factors. Patients found the interface easy to understand and believed it helped them manage their diabetes and communicate better with providers.

EXPANDED MANAGEMENT AND PREVENTION MODELS

The influence of the social, economic and cultural determinants of health suggest the need for a comprehensive and integrative approach to improving health that addresses the root causes and tries to respond to chronic disease through intervention and management. "Population health promotion"[48]is becoming a common way to integrate the evidence of the broader determinants of health (the population health approach) with the actions of health promotion.[49]

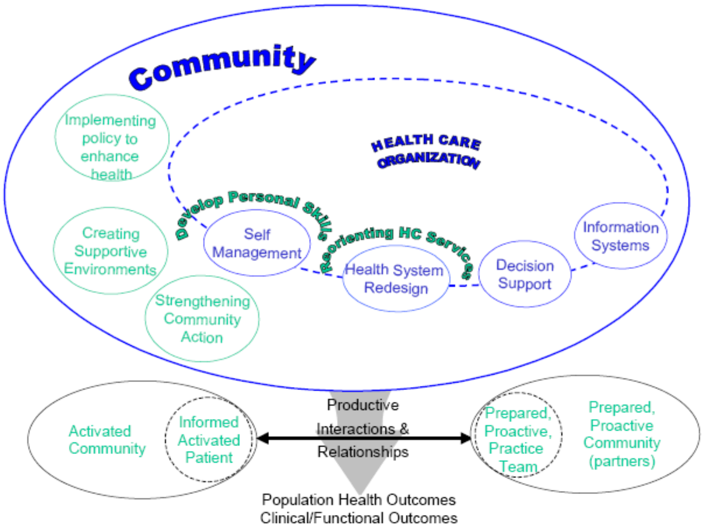
These actions can and should be implemented at a variety of levels and sectors for them to have maximum effect. As the Public Health Agency of Canada[50] recommends, high-quality healthcare services must be supported by policies and programs in communities that allow people time and opportunity to care for each other, prevent problems before they occur and avoid further problems from occurring after injury or illness is already present.

Considering these factors, an enhanced version of the Chronic Care Model has been developed that allows for the integration of population health strategies in the larger community and the involvement of health systems teams outside of the clinical setting. Known as the Expanded Chronic Care Model, this integrated chronic care-health promotion framework was developed in British Columbia (Robinson, 2005) and is being implemented by a large number of health care organizations in the United States, the United Kingdom and Sweden.[51] The model and examples of several integrated chronic disease management and prevention initiatives, from Finland, Sweden, New Zealand, and Australia, are described below.

(1) The Expanded Chronic Care Model (British Columbia)

Going beyond the clinical focus of the Chronic Care Model, the Expanded Chronic Care Model adds extra supports to encourage both individuals and communities to adopt healthy living strategies. As Barr and colleagues note (2003), "this strategy requires action on the determinants of health as well as delivery of high quality healthcare services."[52] It includes six major components: (i) additional self-management supports, located in the community, schools and workplaces; (ii) holistic healthcare systems, involving health care, voluntary and citizen groups; (ii) decision-making process, including both professionals and lay people; (iii) clinical information systems, encompassing determinants of health and outcomes data; (iv) healthy public policies, including affordable and accessible necessities; (v) supportive environments, offering safe and socially sustaining settings; and (vi) public participation, supporting collective action on common goals, needs and proactive solutions.

Figure 4 -- The Expanded Chronic Care Model [53]



(2) North Karelia Project (Finland)

The North Karelia Project, a community-based health promotion program in Finland which focused upon the reduction in cardiovascular disorders, has demonstrated the potential of effective population health promotion at work. The North Karelia Project was launched in 1972 to reduce the exceptionally high coronary heart disease mortality rates in the area. In co-operation with local and national authorities and experts, as well as with World Health Organization, the project was designed and implemented to carry out comprehensive intervention through the community organizations in the area, and the action of the people themselves.[54]

The North Karelia project strategy involved a combination of primary and secondary preventive activities- utilizing the population and the high risk approaches. The special features of the educational program were (i) integration of the program into the community, emphasizing participation and social support, (ii) integrated prevention of cancer, diabetes and heart disease, small-group antismoking, dietary and rehabilitation support, and (iii) environmental support for change through promoting preventive health care services and heart healthy food products.

The integration of the program into the community succeeded well.[55] Changes included the improvement of dietary habits, decline in smoking, and increase in physical activity, with reductions in cholesterol and blood pressure.[56] At the same time, cardiovascular and cancer mortality was reduced more than 50%, leading also to greater life expectancy.[57] The project has now become a major demonstration program internationally, as an example of a community-based approach in which preventive interventions were targeted at the whole population.

(3) The Jonkoping Health Initiatives (Sweden)

Jönköping County Council, a county council in southern Sweden serving a population of less than 340,000 has gained national and international recognition for making and sustaining large-scale improvements in healthcare, including chronic disease management. [58] Two exemplary initiatives, the Esther Project and a Swedish adaption of the Robert Wood Johnson Pursing Perfection Project, were developed.

Esther, an 88-year-old Swedish woman who continues to live alone in the community but has a chronic condition and occasional acute needs, is a persona that was invented by clinicians in Jönköping for the purpose of assisting them in the task of tracking and improving patient flow and coordination for seniors in the county's municipalities. Changes made included a redesigned intake and transfer process, open access scheduling, team-based telephone consultation, integrated documentation processes and self-management education[59] The project yielded impressive improvements, including overall reduction in hospital admissions, redeployment of resources to the community, reduction in hospital days for heart failure and reduced wait times for specialist appointments.[60]

Based on the Esther's success, Jönköping County Council[61] also adapted elements of the Pursuing Perfection Project, developed by the Robert Wood Johnson Foundation in the United States.[62] Key changes included role redesign with occupational therapists and nurse practitioners having more enhanced follow-up roles. Outcomes included increased rates of influenza vaccinations, reduced rates of asthma hospitalizations, and substantial reductions in acute care hospital admissions, morbidity and mortality among the elderly. Jönköping County was considered the highest performing of all Pursuing Perfection sites, financially and "that gains are possible when innovative design meets rational resourcing." [63]

(4) Care Plus (New Zealand)

In 2004, the New Zealand Ministry of Health launched Care Plus, a new service for people with chronic disease delivered through Primary Health Organisations (PHOs).[64] The key feature of the Care Plus program was the identification of people with diabetes, chronic obstructive pulmonary disease, cardiovascular disease, asthma and arthritis who required intensive case management and the provision of additional funding to support services. Once identified and enrolled, patients were entitled to care planning with quarterly checks and self management support. Initial pilots were directed towards four health regions that had high percentages of low income families and significant percentages of Maori and Pacific Islanders.

Early evaluations suggested that the program had been successful and had reached large numbers of clients with complex chronic conditions. [65] Patients believed that their care had improved under the program and especially appreciated the structured visits and supports. Most of the providers believed that having skilled nurses in the care planning role, either taking the lead or working with physician team leader, improved overall chronic disease management.

Some practices, however, had difficulty implementing the program because the time and staffing required were in excess of the funding allocated. Another barrier to implementation was the fact that older males and the very elderly were unwilling to take a more active role in their care and declined to participate. Other practices felt that insufficient resources were allocated to improving the practice information system and staff training, both of which were important in preparing the practice to maximise both the enrolment and funding available for the Care Plus program.

(5) Aboriginal and Torres Strait Islander Health Initiatives (Australia)

The Queensland Health Region, in partnership with Indigenous organisations, developed an Enhanced Model of Primary Care (EMPHC) to achieve improved health in the rural and remote areas of the Northern Zone, where 9 per cent of the population identifies as Aboriginal or Torres Strait Islanders.[66] This population has a life expectancy 20 years lower, a higher burden of diabetes, heart disease, hypertension and renal disease, and hospitalisation and death rates as much as four times higher than their non-Indigenous counterparts.[67] [68] National statistics confirm 36 per cent of Aboriginal adults have a disability or long term condition.[69] Access to care also is problematic, as 70 per cent of the population live in rural or remote areas.[70]

The Queensland Health Audit and Best Practice for Chronic Disease (ABCD) project[71] assessed several interventions that were designed specifically for Aboriginal and Torres Strait Island populations. Reviews suggested that the most effective programs were those which improved the delivery system by supporting development of indigenous disease registers, multidisciplinary team care, recall systems and care planning.[72] Pooling of funding to support access to physician primary care services and investment in infrastructure, and care planning also produced improvements.[73]

Other projects demonstrated that self-management employing Aboriginal health workers were successful in enhancing patient outcomes.[74] Secondary prevention programs such as dietary interventions have also improved health but were difficult to sustain.[75] Over the long term, the most successful programs appear to be those which are built from the "bottom up" and have high degree of community involvement and commitment from local residents.[76]

ONTARIO'S CHRONIC DISEASE PREVENTION AND MANAGEMENT FRAMEWORK

Planners and decision makers are challenged to find evidence-based information on best models that could guide planning and implementation of integrated health systems,[77] however, primarily due to the fact that current knowledge regarding the concept of integration as a component of chronic disease management is generally diverse and scattered. The complexity of health care delivery systems, the diversity of populations served, geographical issues, jurisdictional challenges and varying client needs add further challenges to the development of a unified model.[78]

In a 2005 Commonwealth survey[79] [80] of chronically ill adults, Canadians reported the following gaps and or redundancies in care: conflicting information from different doctors or health care professionals (25%); test results not available in time for appointment (19%); duplicate tests (10%); professionals failed to share patient care information with other professionals (13%) or with patients (15%); patients did not receive hospital discharge instructions (17%); discharge plans did not arrange for follow-up visits (30%); discharge plans did not provide patients with plans to help manage their own care (35%). In addition to these gaps, results from a survey published in 2008 by the Health Council of Canada indicate that only 14% of Canadian physicians regularly provide patients with written instructions on managing their chronic conditions at home[81], an indication that gaps in chronic disease management continue to be prevalent in the Canadian medical system.

In order for transitions to occur successfully between points of care, clinical histories, test results and discharge plans must be accessible to all providers involved in an individual's care, if this level of accessibility is not provided, patients are more likely to encounter gaps in care and may be left without the resources (i.e., knowledge and support) they require to manage their own care.[82] Given these challenges, integration of chronic disease management and prevention initiatives has been identified by the Romanow Commission on the Future of Health Care (2002) as being a necessary means for ensuring the accessibility and integrity of healthcare for Canadians.[83]

To address these challenges, the draft Ontario Chronic Disease Prevention and Management Framework (2005), was designed to assist Ontario in the shift from an acute care focused health system, to a system that seeks to improve clinical, functional and population health outcomes by fostering elements such as coordination and integration. Following the approached developed in British Columbia (Robinson, 2005) , the Ontario framework allows for the integration of population health strategies in the larger community and the involvement of health teams outside clinical settings.

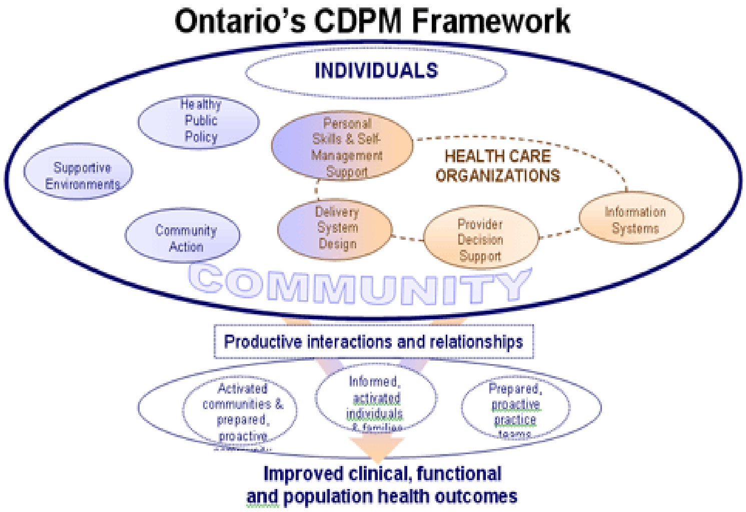


Figure 3: Ontario's CDPM Framework (after Wagner 1998) [84]

The proposed Chronic Disease Prevention and Management Framework builds on central aspects of the Expanded Chronic Care Model.[85] The Expanded Chronic Care Model takes lessons learned from the management of chronic disease and utilizes them in combination with health promotion on a population level. By combining these two approaches and the evidence base supporting them, the goal is to prevent the development of chronic disease.

To provide an evidentiary basis to assess the feasibility of applying the expanded model, Ontario Chronic Disease Prevention Alliance recently completed an environmental scan of chronic disease prevention and management strategies in Ontario.[86] This scan concluded that the development of effective strategies was impaired by a lack of prevention focus in some disease strategies, varying influence on private sector industries, inconsistent application of social marketing, an absence of planned cross-risk factor communications, competing research strategies and consistent outcomes indicators.

Public policy supports and infrastructure to support health integration and promotion, including knowledge transfer, health professional development and retraining initiatives, were also lacking. Inadequate or ineffective working relationships among public and private organizations, inconsistency in knowledge translation and exchange activities, multiple specialty planning organizations, and poor connectedness, particularly in program and policy planning, were identified as significant barriers to developing integrated initiatives.[87]

CHRONIC DISEASE IN THE NORTH WEST LHIN

As Bain and colleagues report in *Chronic Conditions in the North West LHIN* (2007), almost three-quarters of the residents aged 12 and older (74%) completing the 2005 Canadian Community Health Survey (2005) had at least one chronic condition, with arthritis (21.4%) or hypertension (18.%) being the most commonly cited chronic conditions.[88] The proportion of the population having multiple chronic diseases also was higher in the North West LHIN: almost one-third of residents aged 45 or older (33%) and one-half of those aged 65 and older (52%) had two or more chronic conditions, with both age groups above the provincial averages (27% and 46%, respectively).[89]

Canadian Community Health Survey data also reveals prevalence rates for arthritis (21.4), hypertension (18.5) and heart disease (6.5) were significantly higher than the provincial rates for the same conditions (17.2, 15.4 and 4.8). Comparison of CCHS rates to provincial registry data for diabetes, however, suggests that this condition is under-reported, possibly due to the fact that the CCHS does not survey First Nations populations living on reserve.

Information from other provincial health databases suggests that chronic disease is placing higher demands on primary and acute care systems than are experienced in the rest of the province. As reported in Bains (2007), the North West LHIN (*Table 1*) has significantly higher rates of mortality on seven of the eight major chronic conditions, asthma being the exception. Rates of hospital separations, emergency department and family practitioner visits for cancer, diabetes, depression, heart disease, hypertension, stroke, asthma, COPD and arthritis are also above the provincial average.[90]

Table 1
Mortality, hospital separation, emergency department visit and GP/FP Visits, per 100,000 population, for North West LHIN / Ontario (Data from Bains et al, 2007)

Condition (All Ages)	Mortality Rate (2001-03 Average)		Hospital Separation Rate (2005-06 Fiscal)		Emergency Department Visit Rate (2005-06 Fiscal)		GP/FP Visit Rate (2005-06 Fiscal)	
	NW	ON	NW	ON	NW	ON	NW	ON
Cancer	221.8	198.5	447	483	164	118	4,301	2,893
Diabetes	39.4	25.8	184	97	431	186	10,712	12,176
Depression	1.0	0.5	233	143	488	273	2,365	3,600
Heart Disease	186.3	157.0	823	551	592	380	5,120	5,714
Hypertension	6.3	6.2	26	20	288	178	22,494	32,413
Stroke	49.1	43.2	279	166	261	208	841	854
Asthma	0	0.8	98	67	950	575	3,625	5,162
COPD	44.3	30.8	353	211	1,110	610	2,697	2,224
Arthritis	4.0	2.9	445	328	2,910	1,346	12,781	15,620

Source: Bains, N., K. Dall, and J. Hohenadel. (2007). *Chronic Conditions in the North West LHIN. Health System Intelligence Project (HSIP) Report.* Toronto, ON: Ministry of Health and Long-Term Care. (p. 9, 11, 13, 15, 17, 19, 21, 23, 25).

The NW LHIN also has a higher prevalence of modifiable risk factors associated with chronic disease (*Table 2*). Residents aged 12 and older were significantly more likely to have poor diets (less than 5 servings a day of fruits and vegetables), to be heavy drinkers (5 or more drinks on one occasion more than 12 times per year), smoke (daily or occasional), and have hypertension than the province overall, although they less often reported being physically inactive. More of the region's population aged 18 and older, however, had weight problems, with one-third meeting the criteria for being overweight and one-fifth considered obese.[91]

Table 2

Risk Factors – Prevalence of common modifiable risk factors (prevalence per 100,000 population) (Data from Bains et al, 2007)

Factor	NW LHIN	Ontario
Poor diet (less than 5 servings of fruit or vegetables per day)	59.9	53.8
Heavy drinking (more than 5 drinks x 12 occasions per year)	28.6	22.1
Smoking (daily or occasional smoker)	25.7	20.8
Physical inactivity	41.1	46.0
Hypertension	18.5	15.4
Obesity (age 18+) (BMI 25.0 to 29.9 kg/m2)	22.3	15.2
Overweight (age 18+)(BMI greater than 30.0 kg/m2)	36.9	33.6

Bains, N., K. Dall, and J. Hohenadel. (2007). *Chronic Conditions in the North West LHIN. Health System Intelligence Project (HSIP) Report.* Toronto, ON: Ministry of Health and Long-Term Care. (p. 27).

Bains and colleagues noted that reduction in exposure to these behavioural risk factors could markedly reduce the burdens of chronic disease in the North West LHIN. Although they noted that further analysis of the associations between socio-economic conditions and behavioural risks was needed they concluded that their analysis:[92]

> … Shows that a considerable proportion of chronic disease is avoidable. In Ontario, tens of thousands of cases of diabetes, heart disease, stroke, COPD, cancer and osteoarthritis could be prevented through reductions in smoking and alcohol misuse, increased physician activity and consumption of fruits and vegetables and attainment of healthy weights. Rates for smoking, heavy drinking, obesity and poor diet are all significantly higher in the North West LHIN compared to Ontario overall.

IMPLEMENTING CHRONIC DISEASE MODELS IN THE NORTH WEST LHIN

With respect to the status of chronic disease and chronic disease management and prevention programming in the Northwest Lakehead Health Integration Network area, information gleaned from interviews suggests that a majority of the Family Health Teams and Community Health Centres in the North West LHIN have a chronic disease management system in place. Most communities also have some preventive programming in place, though the type of activity and target populations vary from one location to the next. Barriers such as limited funding and resources, remote locations and a lack of communication between organizations and service providers both within the communities and at a regional level, however, continue to hinder the development of chronic disease prevention and management networks.

Although no comprehensive chronic care models were in place and fully functional in the North West LHIN at the time the study interviews were conducted (December through March 2009), the Chronic Disease Management Model (Kaiser) and the Chronic Disease Self-Management Model (Stanford) were being implemented in several locations. Organizations were also moving towards the development of chronic disease programs, by ensuring staff had access to best-practice guidelines, conducting needs assessments, researching existing chronic disease management programs and obtaining community input to determine the types of programs to offer.

Needs Assessments

Health care providers from community health centres, district health units, rehabilitative programs and volunteer organizations, noted that they routinely conducted needs assessments as a first step in developing programs targeted towards clients with chronic diseases such as asthma, hypertension, high cholesterol, arthritis, stroke, chronic obstructive pulmonary disorder, and diabetes. The role of the community in the development and implementation of chronic disease management programming was significant. Outlining the process of developing a strategy appropriate for her small town, an administrator emphasized the importance of consultation with community providers:

> We determined our chronic disease strategy by first doing a needs assessment … a lot of community meetings … met with the community stakeholders, the community providers… utilized documents that had been previously prepared … from places like the CCAC, the Health Unit, what they were seeing, what they were doing, the mental health program, the senior's program, the children's program, … to determine what were the gaps in the community? What were the barriers to care?

Best Practice Guidelines

Because best-practice guidelines tended to be discipline-specific, there were no "formal care pathways" in place at most organizations to guide practitioners in implementing chronic disease management and prevention programs. In most settings, primary health care providers assumed responsibility for educating themselves on current best practice guidelines and operating within the guidelines. Through case management conferences, they also shared best practice information with their colleagues within their organization and, as the opportunity arose, with other providers in their community. Speaking to this issue, an manager said:

> At the moment, we don't really have our own body of practice guidelines for how we do things, our primary care staff have made a point of educating themselves about best practices and through case management, case conferences … guide their practice of chronic disease management.

Transitioning to Team Care

Adaption of chronic disease management approaches was complicated it required that their organizations move from management by individual physicians to team based care. Administratively, making the transition required numerous adjustments, to ensure that all staff had good awareness of chronic disease management practices and that the supports were in place to ensure that best practices could be implemented effectively. As an administrator noted, this took time and extra effort, on the part of physicians and all the allied health professionals who were part of the team:

> Currently each physician is independently managing patients and their chronic diseases … but we're now in the process of implementing flow sheets .. to the nurses and we're going to be … moving more towards program management as opposed to individual physician to patient management.

Education

Community chronic disease management approaches at the local level also utilized a variety of educational supports, for both clients and providers. Respondents indicated that self-management and chronic disease educational resources, such as “pamphlets and videos”, were readily available for patients. Availability of community-oriented self-management programming and formal educators, however, differed greatly from one location to the next. In some communities, there were formal education services, such as cardiac rehabilitation or diabetes education, available through local hospitals. In other towns, specialized educational supports were available through the Health Unit or community Social Services agencies. Looking around her community, one of the smaller towns in the North West, a practitioner said her family health team routinely referred patients to:

> … The cardiac rehab which takes place at the hospital, the depression group through medical counselling, lots of agencies have education and support, like the Health Unit does a lot of things, particularly around disease prevention and some self-management, again, the family health team will partner with those agencies to fill in any gaps that there might be.

Health care professionals, such as community registered nurses, were reported as being actively involved in and engaged in the provision of chronic disease and self-management education. In some cases, registered nurses were educating themselves for the purpose of becoming ‘expert educators’ on specific diseases, such as asthma, COPD or diabetes and, once certified, shared their knowledge with other personnel. Some communities also had mental health counsellors who had special expertise in group counselling for patients and caregivers who were coping with chronic disease:

> The other piece in our chronic disease management program is we also do group programs for mental health as well. Looking at groups of individuals with mental health disorders and chronic disease, we also do relationship counselling, anger management, living with a change, such as job loss, anything that would be considered change in someone’s life.

Those who were interviewed for the study appreciated recent workshops and courses on the Stanford Chronic Disease Self-Management Model. The Stanford Chronic Disease Self-Management Program Model was implemented or in the process of being implemented in most of the organizations surveyed. Group-based programs such as the 'It's Your Health/Manage Your Health' programs were being offered. Other programs, such as diabetes education sessions, were being offered by various organizations, including community organizations, hospitals and family health teams.

Targeted Programs for At-Risk Populations

Programs targeted toward population groups at risk, were less-common and were often disease-specific (i.e., diabetes program) as opposed to population-based. Services that were population targeted included: patient-navigation programs or patients with comorbidities, and Aboriginal traditional healing programs for the First Nations population. Several locations reported that they were delivering community-based combined prevention and screening programs that were accessible to the public, in workplaces, schools, senior centres, or housing units:

> We have gone out into the schools … we go the community housing, because some of the people there cannot come to us so we go there for two hours or so and provide screening, blood pressure checks and a twenty-minute education session. So we've done stress prevention, diabetes prevention, stuff like that.

Electronic Medical Records

Electronic medical records within clinics and communities were available and accessible, however, often reported that the physicians and other organizations were hesitant to share patient medical data. Survey results indicated that electronic health supports were being implemented and/or developed within most of the regions of the LHIN surveyed.

Electronic medical records were viewed as being beneficial to the general health care practice, as were practice supports, such as appointment reminder systems. In cases where electronic health resources were not available, funding was identified as a key barrier to the incorporation of electronic-based medical data systems. Only one of the family health teams surveyed (Dryden) was completely 'paperless,' and had an established electronic medical record system in place which all community health professionals utilized to chart patient data. Family health teams, health centres, hospitals, along with community-based service-delivery agencies, used a variety of electronic and paper record keeping systems. There was, respondents acknowledged, a steep learning curve for both administrators and front-line staff in transitioning to e-record systems. Some clinics didn't have enough administrative supports in place to ensure that some elements of the systems, such as practitioner or client reminders were fully operational. Other primary care organizations didn't have enough administrative staff in place to set up the system so that it was fully operational.

There were also no policies or program supports in place to ensure that electronic systems, when implemented, could be networked. Several examples were reported of clinics, for example, being able to access their own records, but not being able to access other information, such as test results, that were held by hospitals or community laboratories. Similar gaps in communication occurred, for example, when providers didn't have time to enter information on clients with diabetes in both the Diabetes Registry and their own systems. As a clinic administrator reported, incompatibility of electronic record-keeping systems and a lack of resources to address the problem was a major impediment to creating effective chronic disease communication networks:

> We've been using an electronic health record for at least 5 years if not longer and I'm aware that the family health team is implementing one and I believe they have one at the hospital, I do know that none of them communicate with each other …. realistically we have been struggling because we have a limited administrative capacity and so people don't see the result back from what they put in … and then there's those limitations of still having to do some separate thing to communicate with caregivers and providers.

Integration Issues

Although health care organizations were moving towards implementing chronic care management, there was limited integration of programs at the community and regional levels. Networks were typically limited to the community and in most cases the existing networks were not 'formal.' The success of networking was dependent upon factors such as physician participation and communication between organizations, the majority of health team members surveyed, indicated that their chronic disease management networking capabilities were limited.

There were, however, several examples in which family health teams had begun the process of creating an effective and efficient chronic disease network for their communities that would ensure clients had access to the best care available. A health care administrator from a family health team reported:

> One of the biggest things we did was network with the community and the other organizations who might be doing bits and pieces of chronic disease management… to strengthen the network … to communicate with each other and then decide how we could best facilitate chronic disease management for patients in our area without duplicating

> services … patient navigating through this system as easily as possible but making sure that they're not falling through the cracks.

The lack of communication between healthcare providers was reported to be impacting the manner in which information is shared between organizations, to the extent that health care organizations were operating within separate silos, resulting in a lack of collaboration between the various organizations. A demonstrated reluctance on the part of some physicians to share patient's medical information with health personnel in the family health teams and front-line health providers was identified as a specific problem.

This occurred, typically, where a client had been referred to another organization for physician consultations, tests, or other assessments and there had been a significant delay in getting the information back to the primary care provider. Health personnel, for example, at an outreach clinic, reported that not having immediate access to a particular patient's blood work, x-rays, reports from the doctor etc. caused significant delays in care. These types of communication problems also occurred when clients were referred to community-based agencies for assessments, education or supportive care:

> There's poor communication between other agencies .. we don't have a communication set-up, there's barriers, when we call someone … we don't get a report, we don't know what's going on with our patients.

Health professionals who had been actively involved in trying to address these issues observed that some providers were sceptical about the degree of integration that was necessary in the management of chronic diseases. Issues related to the sharing of data and patient consent regarding the sharing of data were commonly encountered during the implementation of chronic care programming.

Lengthy Waiting Lists

Management of clients with serious chronic conditions was made more difficult by the fact that the waiting lists for an appointments with primary care providers or referrals to specialist care were “too long.” Patients in some of the smaller communities that had shortages of family physicians, reportedly had to wait up to “three months” for an appointment. Other clients found themselves facing a delay of “two to four years” to access services from visiting specialists.

Providers suggested that lists should be prioritized in order to ensure that the patients who require urgent care, receive it. To follow best practice guidelines for arthritis, for example, patients diagnosed with early rheumatoid arthritis must be seen, diagnosed, and started on medication (drugs and, in some cases, chemotherapy) within a period of approximately three months, in order to prevent further damage to the body. The development of a triaging process to identify patients who require urgent medical care would greatly improve a patient’s ability to access the timely care that they require.

Lack of a Common Chronic Disease Strategy

In regards to the lack of integration, some key informants expressed concern regarding a perceived lack of a clear chronic disease management and prevention strategy for the North West LHIN region. The general sentiment from some was that without a clear strategy, health care organizations would continue to implement and follow separate prevention and management strategies with everyone “doing their own thing.” The lack of a strategy was viewed as impacting the delivery of programs and services, as well as the level of coordination between health organizations.

Many interviewees felt that improved coordination was necessary for the successful implementation of self-management programs within their community. Several informants observed that different organizations focussed on specific areas of care and, in many situations, the organizations were unaware of what areas the other organizations were focused on. This sometimes lead to duplication in services. More often, it created gaps in service, to the detriment of both clients and providers. They emphasized:

> We need to look at our programs and how they interface …we have 8 or 9 physicians here, they are doing ER, long-term, supportive housing, home visits, primary care, we need to have these services integrated. We also need support for community mobilization, ensuring there's a platform

Transitions to Team Care

Family health team personnel reported having limited staff and limited funding and in many cases, simply did not have the resources or time necessary to provide programming to every patient who suffered from a chronic disease. Given the shortage of physicians and increasing volume of patients that were presenting in primary care practices, however, appointments were often only "3 to 5 minutes long," which meant there was little time for physicians to address anything other than the most basic clinical issues:

> The doctors aren't doing chronic disease management, they're relying on the other programs that we have in place to do that. So they're not doing the education, they're not doing the prevention component, they don't have the time. We are five physicians short in our area and so they're seeing and getting dozens and dozens of patients in a day because people have to wait for three months, they don't have the luxury of spending twenty minutes to a half an hour for each patient.

Reluctance to Change Established Practice Patterns

A demonstrated reluctance on the part of both health care organizations and individual providers to modify entrenched practices and guidelines also has functioned as a barrier to both integration and the progress made in the development of chronic disease prevention and management programs. The shift from acute care to the management of chronic disease was described as a significant shift involving extensive resources.

Observations regarding the health system and its focus upon the needs of health professionals as opposed to those of the patient were also made apparent, especially pertaining to the critical role that the physician holds in relation the process of patients learning self-management skills. Several interviewees noted that physicians and other primary care were so over-burdened with meeting acute care needs of their clients that they had no time to invest in management activities that involved communication with other providers and organizations. As an interviewee said:

> There’s no time to do management activities. People’s workloads are too heavy so they don’t want to attend meetings and do that kind of reflective discussion … communication is an issue, but not a root problem, it’s more of a symptom of other things. You have to have a certain amount of time and energy to invest in communication issue across the board, there has to be some understanding as to why the communication is required and who needs to know what, but we don’t really have the time and energy to pay a lot of attention to.

A lack of time and energy to invest in the development and implementation of chronic disease management and prevention programming was also regarded as a factor associated with the reluctance to change established practice. Additionally, it was apparent that there exists a lack of general comprehension in regards to the nature of chronic disease management programming within the health sphere, concepts inherent in CDPM programming, such as the role of chronic disease management pathways of care, in some cases, were not fully understood within the health community.

Lack of Funding

A key barrier that was discussed in a number of interviews was an acute lack of funding for health programming and family health teams. Administratively, the development of effective and integrated electronic medical and health systems to support chronic disease management was viewed as wholly dependent upon the availability of funding. The quality of programming offered by health teams, hospitals and community organizations also was affected by the funding available to support training of health care practitioners and resources, such as workshop materials, to support local education initiatives.

Another issue was the fact that funding for various types of chronic disease programming, including self-management education initiatives, continued to be offered on a disease-specific basis. As a program manager noted, "siloed" funding for client services was one of the major impediments to developing an effective chronic disease prevention and management strategy, at the community or regional levels:

> They need to develop a strategy … funding is in silos, so you have diabetes gets money, stroke gets money, heart gets money and we're all fighting for the same dollars. So, if you're going to develop a chronic disease prevention and management system, you need to pull the money together and get everyone working together, otherwise we're all competing for the same dollars.

Geographic Location

Individuals residing in Northwestern Ontario towns and First Nations communities continue to encounter difficulty in regards to accessing chronic disease management programming and services and are not receiving the ongoing support and care necessary to manage their health conditions. The development of electronic medical records and electronic health resources was also impacted by geographic considerations, with smaller communities lacking reliable access to the Internet.

Geographic location also meant that health professionals were isolated from their colleagues and health care resources available in larger centres. Health professionals in rural areas often described working within ‘silos’ with few physicians, due to rural location and recruitment difficulties. They also noted that patients residing in rural locations were subject to lengthy wait-lists for physician appointments and were unable to access specialist services.

Additionally, networking does not appear to be occurring on a regional basis. Some family health teams reported that in terms of chronic disease management programming they are generally operating on an independent basis. Some respondents saw value in “involving the regional hospitals, having them available to rural communities, in the area of chronic disease and medicine technology.” Others noted that implementation of chronic disease management strategies was hindered by a general lack of awareness among the public about what chronic disease management is. On this subject, an interviewee suggested “there needs to be advertising as to what chronic disease management is and health promotion, so that the community can start breaking away from acute care” and move towards a more inclusive understanding of health.

IMPROVING CHRONIC DISEASE MANAGEMENT IN THE NORTH WEST LHIN

In regards to the improvement and enhancement of existing chronic disease management and prevention programs, the health care administrators and practitioners that we interviewed offered a number of suggestions for improvement in chronic disease management and prevention. Their suggestions, summarized in the sections which follow, offer.

Increased Funding

Increased funding for the development and implementation of Chronic Disease Management programming was a primary need addressed by all health professionals in the interviews. The degree of health care community coordination in regards to networking and programming was also identified as an area where improvement was needed. It was suggested that resources be designated to support electronic health resources and education regarding the role of integration and communication in the management of chronic diseases.

Practice Changes Supporting Self-Management

With the concept of self-management at the core of chronic disease management and prevention programming, it was made apparent that in order to meet the needs of patients who are managing their chronic illnesses, physicians must be accessible and available to patients when they have inquiries regarding their disease. The current situation of month-long wait lists and fifteen-minute appointments was identified by health care providers as being particularly problematic for patients involved with self-management. Given the health human resource constraints experienced across the region, the need for the establishment of target populations, in relation to available programs and services was also suggested as a solution to long wait times. Some health professionals also felt that targeting programs towards those at risk would improve program effectiveness, by ensuring that services were adequately reaching or directed at the populations that were most in need.

Provider Education

The need for improved education regarding chronic disease management and prevention and programming was also made apparent. Several respondents suggested that the LHINs should support additional educational (workshop) opportunities and guidance regarding the development and implementation of Chronic Disease Management Programming. Additionally, it was observed that such education should be made available to those who are attending medical school.

A key problem highlighted by many, was that there was a significant lack of knowledge regarding the nature of chronic disease management and prevention within the medical community. Others emphasized that there exists a clear need for some level of knowledge in regards to the definition of chronic disease management. There was also a desire for clinical education for providers to assist them in managing chronic disease related conditions, such as wound care.

E-Health

In regards to issues involving communication and the development of electronic medical resources, the need for the development of a singular electronic medical record system was reiterated in a number of the interviews. The health professionals interviewed, clearly stated that improved access to patients' health records, laboratory reports and physicians' notes was a key element to ensuring that patients received the care that they required on a timely basis.

Health professionals were generally eager to implement electronic medical records; however, in some cases, such networking between organizations was not occurring and, even within organizations, physicians were not charting data in the electronic medical record system. Where e-records had been implemented, some aspects of the system, like reminders, often were not fully functional. The consensus was, however, that electronic records were valuable:

> The electronic medical record has been implemented really well. There's only docs that aren't using it. Our electronic medical record has little logos that tell you what chronic conditions people have … We all write on the electronic medical record, so it's easy to share record because you can read what people have written but if you're asking me … like let's say for instance somebody needs a pap smear … as far as I know our electronic record doesn't do that .. But we do share information and we know that someone has a chronic disease … but it's not really developed.

Policy Supports

Interviewees were in agreement that limited infrastructure and resources in the communities of the North West LHIN have impacted the manner in which they are able to network with other health organizations and provide effective chronic disease management and preventive programming to their patients. In this respect, health human resource shortages across the region were viewed as important service gap both for service providers and for patients.

The absence of supportive transportation policies also was a serious barrier to accessing care for seniors and people with disabilities who lived in rural areas, small towns or First Nations, where there was no public transport available to give them access to health care organizations located in adjacent communities. Unless outreach services were available, they could not even access primary care:

> The seniors that I'm dealing with … they're 70 and older, many do not have vehicles, and their families are out of the community, so they rely on friends for transportation and often they won't bother their friends … seniors who have not had any access to health providers for a long time. Transportation in the winter is a huge issue, investing in … transport buses … would provide more access to seniors. I know we're a rural community, but it's distance to get to the clinic, if you're disabled or elderly, it's difficult.

Given these issues, there was a consensus that effective implementation of a Chronic Disease Management framework for the North West LHIN was a priority. Respondents also expressed a desire for a greater degree of input into framework development and implementation from all stakeholders involved in the provision of health services across the region, in urban, rural and remote communities,. The current situation clearly indicates that there is a degree of separation between existing frameworks that emphasize chronic care management and prevention strategies and the actuality of program implementation.

As our interviewees observed, a comprehensive framework for chronic disease management and prevention requires collaboration among numerous stakeholders, considered assessment of determinants of health and populations at risks, and development of appropriate strategies that involve local health care providers and representatives of the communities which they serve. Chronic disease prevention and management inherently involves multiple levels of responsibility and requires integration, networking and communication in order to assist in the management and prevention of chronic disease.

Ongoing research, program and policy development, are critical components in the development of a chronic disease prevention and management strategy. Communication between health professionals and patients involved in chronic disease prevention and management must be improved in order to ensure that patients are receiving the level of care necessary for the management of their chronic disease. On this last issue, there was a recognition that the development of effective chronic disease prevention and management could be improved by putting time into focussed consultations to ensure that planners, policy and decision-makers were fully informed about challenges and opportunities that existed on the front-lines. As a practitioner said:

> There should be more consultation and dialogue with front-line people .. . the family health team executive directors and other front line people as to what the needs are with this whole program, so more dialogue and consultation.

APPENDIX A

Centre for Rural & Northern Health Research

Centre de recherche en santé dans les milieux ruraux et du nord

"Environmental Scan: Chronic Disease Prevention and Management for the NW LHIN"

Interview Questions – Key Informants

The purpose of this research, commissioned by the North West Local Health Integration Network, is to explore the factors affecting chronic disease management and prevention in Northwestern Ontario communities. Research indicates that integrated initiatives, including practice guidelines, intensive case management, along with supports for self-management and disease prevention, produce measureable benefits for both providers and clients. As a professional working in the health sector in Northwestern Ontario, we are interested in hearing your opinions about how effectively such best practices have been implemented in your organization, your community and our region:

1. Thinking about your organization, how have chronic disease management strategies been implemented?
    a. Does your organization have practice guidelines in place for management of clients with chronic conditions? how do you incorporate best practices into your daily client-care activities? (e.g. clients with diabetes, heart failure, asthma? for clients with multiple chronic conditions? clients with dementia or Alzheimer's? clients without regular physician or nurse practitioner care?)
    b. Does your community have a chronic disease management network in place? (If so, does it include primary care clinics, home care organizations, hospital, public health unit, volunteer organizations, etc.? is it targeted towards specific diseases, or is it a generic model? If none, are plans in place to establish such a network?)
    c. Which providers in your community are primarily responsible for implementing best practices for clients with chronic diseases? (e.g. physicians, nurses, case managers? is enhanced case management provided for clients with multiple chronic conditions? in your opinion, how effectively have best practices been adopted in your community?)
2. Does your community have education and other supports to assist clients with self-management and disease prevention?
    a. If any, what types of educational resources are available? (e.g. educational pamphlets, videos? referrals to counselling, support groups? do providers routinely refer clients to these resources?)
    b. Any special self-management programs for population groups at risk? (e.g. low-income families, rural residents, Aboriginal, Francophone populations? clients with comorbidities? with dementia or Alzheimer's? which are most at risk? are existing resources devoted to them?)

   c. Any health promotion and chronic disease prevention initiatives? (e.g. community wellness, healthy lifestyle, physical activity programs? are these generic initiatives or targeted towards specific diseases? targeted to populations at risk?)

3. To what extent have electronic records and other e-health supports been implemented to assist with chronic disease prevention and management?
   a. What types of e-health supports are in place? (e.g. e-records, e-registry, e-reminders? e-mail or web-based information for providers? clients? are the systems integrated? if not, do providers have to enter data into several systems?)
   b. Which organizations and provider groups in your community use the systems? (clinics, hospitals, community care, other? physicians, nurses, case managers, pharmacists, other professionals and paraprofessionals? do the systems help providers ensure that clients are monitored appropriately?)
   c. What would encourage organizations and providers to make more extensive use of computer-based systems for chronic disease management? (better information systems? links to community organizations? links to specialists?)
4. What do you feel are the most significant barriers to implementing integrated chronic disease prevention and management initiatives in Northwestern Ontario communities?
   a. Lack of financial and staffing incentives to ensure that provider organizations and practitioners work in alignment with each other? (e.g. expertise to assist in practice design and development of integrated initiatives? uncertainty about which integration interventions would work best? no compensation for time spent in care management activities?)
   b. Health human resource and information technology limitations? (workloads too heavy? staff shortages, recruitment and retention problems? reluctance to change established practices? poor communication between organizations? incompatible information systems?)
   c. Lack of awareness or understanding of chronic disease management and prevention best practices? (no opportunities for providers to attend multidisciplinary workshops on best practices? difficulty obtaining guidelines covering generic chronic disease management issues? covering specific disease areas? difficulty obtaining provider and client education materials to facilitate self-management and prevention activities?)
5. What do you think could be done in your community and in the region to enhance existing chronic disease management and prevention capabilities?
   a. Support from within organizations to improve chronic disease management and prevention? (e.g. leadership, championing quality improvement? willingness to realign care management roles? co-ordination among organizations?)
   b. Support at the regional level to develop and disseminate specialized chronic disease self-management and prevention resources? (e.g. coordination and education resources to support community wellness programming? for populations at risk? for clients with comorbidities?)

   c. External funding and staffing supports for organizations to improve chronic disease management and prevention? (e.g. to integrate existing initiatives? to support intensive case management for high-risk clients? to enhance health information systems? to foster development of inter-professional teams?)

6. Can you identify any other service gaps that have negative effects on chronic disease management and prevention in Northwestern Ontario? What measures do you suggest could be taken to address these gaps and enhance the region's capability to provide effective chronic disease prevention and management?

7. Is there anything else you would like to add regarding the challenges of chronic disease prevention and management in Northwestern Ontario?

8. To improve our understanding of these issues, we would like to talk to other providers who have experience delivering services to clients with chronic diseases in your community. Could you suggest the name of one colleague, possibly an administrator, manager or front-line provider, who might have insights into these issues?

APPENDIX B

Centre for Rural & Northern Health Research

Centre de recherche en santé dans les milieux ruraux et du nord

"Environmental Scan: Chronic Disease Prevention and Management
for the North West LHIN"

Covering Letter

Dear Colleague:

The purpose of the study, commissioned by the North West Local Health Integration Network (LHIN), is to explore Chronic Disease Prevention and Management models for the purpose of determining the characteristics and common elements of successfully integrated approaches to prevention and management. Research indicates that integrated chronic disease initiatives, including practice guidelines, care management plans, supports for self-management, as well as disease prevention, produce measureable benefits for both providers and clients.

As you have been identified by the LHIN staff as a knowledgeable professional working in the health sector, we are interested in hearing your opinions about how effectively such best practices have been implemented in your organization, your community and our region. Your involvement would be that of a participant in an open-ended telephone interview, which would last approximately 20-30 minutes. The interview would be scheduled at a time that is convenient for you. Participation in this study is voluntary and you may answer the questions any way that you choose, decline to answer any question, or elect to withdraw your participation at any stage. There are no apparent risks associated with the study and participation will not affect employment or organization's access to services or supports.

With your permission (consent form attached), we will audiotape the interview to ensure that information is accurately recorded. All data will be secured in locked cabinets in the CRaHNR office at Lakehead University, for a period of five years after completion of the study, at this time it will be destroyed. Data will be kept confidential and you will not be identified in any written reports or subsequent presentations. Results of the study will be available through the LHIN after the end of the project.

For further information about the study, please contact us at the Centre for Rural and Northern Health Research. Dr. Mary Ellen Hill, Senior Researcher, may be reached by telephone (collect) (807)766-7278 or email maryellen.hill@lakeheadu.ca. For further information about procedures for maintaining consent and confidentiality, you may contact the Lakehead University Research Ethics Board at (807) 343-8283. I hope that you will agree that such an evaluation is important and will be prepared to help us carry it out.

Sincerely,

Bruce Minore, PhD
Research Director

APPENDIX B

Centre for Rural & Northern Health Research

Centre de recherche en santé dans les milieux ruraux et du nord

"Environmental Scan: Chronic Disease Prevention and Management
for the North West LHIN"

Consent Form

- If you agree to participate in the telephone/in-person interview, please read, sign and date the following consent form and return it by fax to (807) 766-7218. Please also mail the original signed and dated consent form, via mail to: the Centre for Rural and Northern Health Research, Lakehead University, 955 Oliver Road, Thunder Bay, ON P7B 5E1.

The purpose of the study, commissioned by the North West Local Health Integration Network (LHIN), is to explore the concept of Chronic Disease Management (CDM) through the examination of models of integrated approaches to chronic disease for the purpose of determining the characteristics and common elements of successfully integrated approaches to prevention. Research indicates that integrated chronic care initiatives, including practice guidelines, care management plans, supports for self-management, as well as disease prevention, produce measureable benefits for both providers and clients. Results obtained from this study will be synthesized into a report summarizing the findings, which will be forwarded to the LHIN.

Researchers ask that you assist in this study by taking part in a telephone interview. Because we do not wish to cause discomfort to anyone, your participation is voluntary, you are free to answer the questions in any way that you choose, decline any questions you do not wish to answer, and to withdraw from the interview at any time. To ensure that information is gathered accurately, we also ask that you give consent to audio taping of the interview. This will be done with the understanding that all field notes and tapes will be secured in locked cabinets in the CRaHNR office, for a period of five years after the completion of the study, after which time it will be destroyed. All data will be kept confidential and you will not be identified in any written reports or subsequent presentation of the results.

I, ________________________________ agree to be interviewed as part of the Centre for Rural and Northern Health Research study entitled *Environmental Scan: Chronic Disease Prevention and Management for the North West LHIN.*

In addition please check one of the following:

________ I give permission to the researchers to audiotape the interview.
________ I do not give permission to the researchers to audiotape the interview.

________________________ ________________________
Signature Date

REFERENCES

Alberta Health and Wellness , 2000.

Anderson M. & Parent, K. (2004). "The team approach to hospice palliative care: integration of formal and informal care at end of life." Ottawa ON: Canadian Health Services Research Foundation.

Baker, G.R., A. MacIntosh-Murray, C. Porcellato, L. Dionne, K. Stelmacovich and K. Born. 2008. "Jönköping County Council." *High Performing Healthcare Systems: Delivering Quality by Design*. 121-144. Toronto: Longwoods Publishing.

Bergman H, Beland F, Contandriopoulos AP, et al. "Care for Canada's frail elderly population: fragmentation or integration?" Can MedAssoc J 1997;157(8):1116-21.

Braddock CH, Edwards KA, Hasenberg NM, Laidley TL, Levinson W. "Informed decision making in outpatient practice." *JAMA* 1999;282:2313-2320

Bodenheimer, Tom and Halstead Holman, "Chronic Disease Self-Management in Primary Care." Found at: http://www.coloradoguidelines.org/pdf/ipip/ccm/sms/Bodenheimer%20Patient%20SelfManagement%20Paper.pdf Accessed on November 21, 2008.

Bodenheimer T, Wagner EH, Grumbach K. Improving primary care for patients with chronic illness. JAMA 2002; 288(14):1775-9.

Bowie, J. R. (2006). "The perceptions of continuity of care of rural Albertans following acute myocardial infarction." M.N. University of Alberta, Canada

Canadian Council on Health Services Accreditation [CCHSA], 2006

Campbell, K., Waters, E., O'Meara, S., Kelly, S., & Summerbell, C. (2002). Interventions for preventing obesity in children (Review). *The Cochrane Database of Systematic Reviews*.

Clement S. "Diabetes self-management education." *Diabetes Care* 1995;18:1204-1214.

Coddington, Dean C., Cary R. Chapman and Katherine M. Pokoski. 1996. *Making Integrated Health Care Work: Case Studies*. Englewood, CO: Center for Research in Ambulatory Health Care Administration.

Collins J. Eyre Peninsula Chronic Disease Self Management Project for Aboriginal Communities in Ceduna / Koonibba and Port Lincoln, Report to South Australian Department of Human Services: Eyre Peninsula Division of General Practice, South Australia; 2003 Retrieved June 2005.

Conrad, D.A. and S.M. Shortell. 1996. "Integrated Health Systems: Promise and Performance." *Frontiers of Health Services Management* (Fall) 13(1): 3-40.

D.L. Simel, and J. R. Fesussner. 1995. “A Nurse-Coordinated Intervention for Primary Care Patients with non-insulin –Dependent Diabetes Mellitus: Impact on Glycemic Control and Health-Related Quality of Life.” *Journal of General Internal Medicine* 10 (2) : 590-66.

Enthoven, Alain C. and Carol B. Vorhaus. 1997. "A Vision of Quality in Health Care Delivery." *Health Affairs* (May/June) 16(3).

Fiandt, Kathryn. *The Chronic Care Model: Description and Application for Practice*. 2006; 6(4) Medscape. Found at: http://www.medscape.com/viewarticle/549040 Accessed October 22, 2008: 44-57.

Goodwin, Nick et al. “Managing Across diverse networks of care: lessons from other sectors” Found at: http://www.ijic.org/portal/publish/articles/000046/article_print.html Accessed on November 6, 2008.

Griffiths C, Motlib J, Azard A, Ramsay J, Eldridge S, Feder G, et al. Expert Bangladeshi patients? Randomised controlled trial of a lay-led self-management programme for Bangladeshi patients with chronic disease. Br J Gen Pract 2005;55(520):831-7.

Hamilton, N., and T. Bhatti. 1996. *Population Health Promotion: An Integrated Model of Population Health and Health Promotion*. Ottawa: Health Canada.

Harris Interactive (2005). “Commonwealth Fund international health policy survey of sicker adults.” New York NY: Harris Interactive.

Hayden, Emma et al. “Chronic Disease in Ontario and Canada: Determinants, Risk Factors and Prevention Priorities” Found at: http://www.ocdpa.on.ca/docs/CDP-FullReport Mar06.pdf Accessed November 4, 2008.

Health Council of Canada (2008). “Canadian survey of experiences with primary health care in 2007: a data supplement to Fixing the foundation: an update on primary health care and home care renewal in Canada.” Toronto ON: Health Council of Canada.

Health-Related Quality of Life.” *Journal of General Internal Medicine* 10 (2) : 590-66. *Better Health, 6th IUHPE European Conference*, Stockholm, June 3, 2005.

Hoy WE, Kondalsamy-Chennakesavan SN, Nicol JL. Clinical outcomes associated with changes in a chronic disease treatment program in an Australian Aboriginal community. Medical Journal of Australia 2005;183(6):305-9.

Institute for Clinical and Evaluative Sciences. Diabetes.

Institute for Healthcare Improvement. *Charting the Way to Greater Success: Pursuing Perfection in Sweden.* Cambridge, MA: Author. Retrieved December 14, 2006. Found at: www.http://www.ihi.org. Accessed November 11, 2008.

Integration of Health Care Services: Role of Primary Care. Found at: http://app.reach.gov.sg Accessed on November 6, 2008.

Kennedy A, Rogers A, Gately C. From patients to providers: prospects for self-care skills trainers in the National Health Service. Health and Social Care in the Community 2005;13(5):431-40.

Kennedy A, Rogers A, Crossley M. Participation, Roles, and the Dynamics of Change in a Group-Delivered Self-Management Course for People Living With HIV. Qual Health Res 2007 Jul 1;17(6):744-58.

Leatt, P., Pink, G. H., & Guerriere, M. (2000). "Towards a Canadian model of integrated healthcare." *Healthcare Papers, 1,* 13-35.

Lipscombe L, Hux JE. *Trends in diabetes prevalence, incidence, and mortality in Ontario, Canada 1995-2005: a population-based study*. *Lancet* 2007; 369:750-756.

Luft, H. and M. R. Greenlick. 1996. "The Contribution of Group- and Staff: Model HMOs to American Medicine." *The Millbank Quarterly* 74(4).

Lyons, C. and Anne-Marie Kungl "Ontario Chronic Disease Prevention Alliance: Environmental Scan and Collaborative Alliance Efforts Project" (2005) Found at: http://www.opha.on.ca. Accessed on November 10, 2008.

Marvel MK, Epstein RM, Flowers K, Beckman HB. "Soliciting the patient's agenda." *JAMA* 1999;281:283-287.

McDermott, R., B.A. Schmidt, A. Sinha, Mills P. Improving diabetes care in the primary healthcare setting: a randomised cluster trial in remote Indigenous communities. MJA 2001;174:497-502.

McLennan, J. D., Caza, M., Boyle, M., McWilliam, R., Offord, D. R., Rondeau, K. et al. (2003). "The integration of health and social services for young children and their families" Ottawa ON: Canadian Health Services Research Foundation.

Meera, Jain. "Building the case for change: preventing and managing chronic disease." Ontario Local Health Integration Network (2005)

Metzger, J. *Using Computerized Registries in Chronic Diseases Care*. Oakland, Calif: California Health Care Foundation; 2004. found at: www. chcf.org .

Ministry of Health. "Care Plus: an overview." Wellington, New Zealand: Ministry of Health; 2004.

Ministry of Health and Long-Term Care (Ontario). Presentation to Ontario Chronic Disease Prevention Alliance, 2005.

Mullan, Fitzhugh. 1998. "The 'Mona Lisa' of Health Policy: Primary Care at Home and Abroad." *Health Affairs* (March/April) 17(2): 118- 26.

Naithani, S., Gulliford, M., & Morgan, M. (2006). "Patients' perceptions and experiences of 'continuity of care' in diabetes." *Health Expectations, 9,* 118-129.

Nolte, Ellen and Martin Mckee "Integration and Chronic Care: A Review" Found at: http://www.observatorysummerschool.org/pdf/CDM_Review.pdf. Accessed on October 14, 2008.

Parry, C., Kramer, H. M., & Coleman, E. A. (2006). A qualitative exploration of a patient centered coaching intervention to improve care transitions in chronically ill older adults. *Home Health CareServices Quarterly, 25,* 39-53

Peter Drucker Award: Latin American diabetes Program Found at: http://www.innovation-award.ca/storya5dd.html?IdeabookID=746. Accessed October 31,2008.

Piatt G, Orchard T, Emerson S, Siminerio L, Simmons D, Korytkowski M, Ahmad U, Songer T, Zgibor J "Translating the Chronic Care Model into the community: A randomized controlled trial of a multifaceted diabetes education intervention." *Diabetes Care,* 29(4):811-817, 2006

Des Meules, M. (2005). Toward a Canadian Best Practices System for Chronic Disease Prevention and Control. Presented at *Best Practices for*

Puska, Pekka. *The North Karelia Project: Pioneering Work to Improve National Public Health.* National Public Health Institute. Found at: http://www.ktl.fi .Accessed November 20, 2008.

Robinson, James C. 1998. "Financial Capital and Intellectual Capital in Physician Practice Management." *Health Affairs* (July/August) 17(4): 53-74.

Rollnick S, Mason P, Butler C. "Health Behavior Change. A Guide for Practitioners." Edinburgh: Churchill Livingstone, 2003.

Romanow, Roy J. "Commission on the Future of Health Care: Building on Values: The Future of Health Care in Canada" 2002 Found at: http://www.hc-sc.gc.ca Accessed on November 11, 2008.

Roter DL, Hall JA. "Studies of doctor-patient interaction." *Annual Rev Public Health* 1989;10:163-180.

Schillinger D, Piette J, Grumbach K et al. Closing the loop. "Physician communication with diabetic patients who have low health literacy." *Arch Intern Med* 2003;163:83-90.

Schulz, Rockwell,William E. Scheckler, D. Paul Moberg and Pauley R. Johnson. 1997. "Changing Nature of Physician Satisfaction with Health Maintenance Organization and Fee for-Service Practices." *The Journal of Family Practice* (October) 45(4).

Schwartz, Raymer, Nash, et al. "Hypertension: Role of the Nurse Therapist" *Mayo Clinic Proceedings* 65 (1): 67-72.

Siminerio L, Piatt G, Emerson S, Ruppert K, Saul M, Solano F, Stewart A, Zgibor J. "Deploying the Chronic Care Model to implement and sustain diabetes self-management training programs," *The Diabetes Educator,* 32(2): 2006.

Siminerio L, Piatt G, Zgibor J. "Implementing the Chronic Care Model in a rural practice," *The Diabetes Educator,* 31(2):225-234, 2005.

Siminerio L, Zgibor J, Solano FX. "Implementing the Chronic Care Model for improvements in diabetes practice and outcomes in primary care: The University of Pittsburgh Medical Center Experience," *Clinical Diabetes,* 22(2):54-58, 2004.

Shortell, Stephen M., Robin R. Gillies, David A. Anderson, John B. Mitchell and Karen L. Morgan. 1993. "Creating Organized Delivery Systems: The Barriers and Facilitators." *Hospital and Health Services Administration* (Winter) 38(4)

Solberg LI, Crain AL, Sperl-Hillen JM, Hroscikoski MC, Engebretson KI, O'Connor PJ. Care Quality and Implementation of the Chronic Care Model: A Quantitative Study. Ann FamMed 2006;4:310-316.

Southwestern Ontario Regional Partnership Leadership Forum. "System Transformation and Key Enablers and Integration Strategies" Fall 2006. Found at: http://www.lhsc.on.ca. . Accessed October 24, 2008.

Spragins, Wendy A., Lorenzetti, Diana L. " Public expectation and Patient experience of integration of health care: A Literature Review" Change Foundation. June 2008.

Suter et al. Health System Integration- Definitions, Processes and Impact: A Research Synthesis Found at: http://www.calgaryhealthregion.ca. Accessed on November 11, 2008.

To, T., Gershon A, Tassoudji M, Guan J, Wang C, Estrabillo E, Cicutto L. *Asthma in Ontario. ICES Investigative Report.* Toronto: Institute for Clinical Evaluative Sciences; 2006.

Tasi et. al. A Meta-Analysis of Interventions to Improve Chronic Illness Care *American Journal of Managed Care*, 11: 478-88, 2005.

The Deerfield Group, 2003

The Ontario Chronic Disease Prevention Alliance "Thinking like a system: the way forward to prevent chronic disease in Ontario" March 2006.

Wagner, Edward H. *Managed Care and Chronic Illness: Health Services Research Needs.* Research Agenda for Managed Care. HSR: Health Services Research 32:5 (December 1997)

Weinberger, M., M.S. Kirkman, G.P. Samsa, E.A. Shortliffe, P.B. Landsman, P.A. Cowper,

Wood, Shelley. "Soaring Diabetes over past 10 years in Ontario far exceed WHO projections" *Heartwire* 2007 Found at: http://www.medscape.com. Accessed December 15, 2008

Zwar, Nicholas et al. "APHCRI: Stream four: A systematic review of chronic disease management" Australian Primary Health Care Research Institute. September 2006.

Zuckerman, H. and A. Kaluzny. 1995. "Alliances in HealthCare:What We Know,What We Think We Know,What We Should Know." *Health Care Management Review* 20(1): 54-64.

ENDNOTES

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[1] Hayden, Emma et al. "Chronic Disease in Ontario and Canada: Determinants, Risk Factors and Prevention Priorities" Found at: http://www.ocdpa.on.ca/docs/CDP-FullReportMar06.pdf . Accessed November 10, 2008.

[2] Health Council of Canada, 2008.

[3] Chronic Disease Prevention Alliance of Canada (CDPAC). Chronic Disease Prevention Alliance of Canada.

[4] Haydon, Emma et al. *Chronic Disease in Ontario and Canada: Determinants, Risk Factors And Prevention Priorities.* Ontario Chronic Disease Prevention Alliance and the Ontario Public Health Association. (March 2006). Found at: http://www.ocdpa.on.ca/docs/CDP-FullReport-Mar06.pdf

[5] Bains, N., K. Dall, and J. Hohenadel. (2007). *Chronic Conditions in the North West LHIN. Health System Intelligence Project (HSIP) Report.* Toronto, ON: Ministry of Health and Long-Term Care.

[6] Institute for Clinical Evaluative Sciences. "Intool." Found at: http://intool.ices.on.ca/.

[7] Interviews conducted between December 2, 2008 and March 16, 2009.

[8] These numbers are well above the 8-10 interviews advised as being necessary to achieve information saturation See: Guest, B., Bunce, A. & Johnson, L. How many interviews are enough? An experiment with data saturation and variability. *Field Methods*. 2006; 18(1): 59-82.

[9] Additional ethics review requested by administration of Saint Joseph's Care Group.

[10] Source: Adapted from Wagner EH. Chronic disease management: What will it take to improve care for chronic illness? *Effect Clin Pract.*1998;1:2-4. Available at: http://www.improvingchroniccare.org/change/model/components.html .

[11] Fiandt, Kathryn. *The Chronic Care Model: Description and Application for Practice*. 2006; 6(4) Medscape. Found at: http://www.medscape.com/viewarticle/549040 . Accessed October 22, 2008.

[12] Metzger, J. *Using Computerized Registries in Chronic Diseases Care*. Oakland, Calif: California Health Care Foundation; 2004. found at: http://www.chcf.org.

[13] Garg AX, Adhikari N., Mcdonald H, et al. *Effects of a computerized clinical decision support systems on practitioner performance and patient outcomes: a systematic review.* JAMA. 2005; 293: 1223-1238.

[14] Fiandt, Kathryn. "The Chronic Care Model: Description and Application for Practice." 2006; 6(4) Medscape. Found at: http://www.medscape.com/viewarticle/549040. Accessed October 22, 2008.

[15] Fiandt, Kathryn. "The Chronic Care Model: Description and Application for Practice." 2006; 6(4) Medscape. Found at: http://www.medscape.com/viewarticle/549040. Accessed October 22, 2008.

[16] Feifer C, Ornstein SM, Nietert PJ, Jenkins RG, "Support systems for chronic illness care and their relationships to clinical outcomes." Top Health inf. Manage. 2001; 22:65-72

[17] Shea S Doumouchel W., Bahamonde L. "A meta-analysis of 16 randomized controlled trials to evaluate computer based reminder systems for preventive care in ambulatory systems." J AM Medical Inform Assoc. 1996; 3: 399-409.

---

[18] Sequist TD, Gandhi TK, Karson AS, Fiskio JM, Bugbee D, Sperling M, Cook EF, Orav FJ, Fairchild DG, Bates DW. *A randomized trial of electronic clinical reminders to improve quality of care for diabetes and coronary artery disease.* J Am Med Inform Assoc. 2005; Mar 31;

[19] Barlow J., Eright C., Sheasby J., Turner A., Hainsworth J. "Self-management approaches for people with chronic conditions: a review" Patient Educ Couns 2002:4B 177-87.

[20] Bodenheimer T, Wagner EH, Grumbach K. "Improving primary care for patients with Chronic Illness" JAMA 2002; 288: 1775-9.

[21] Bodenheimer T, Wagner EH, Grumbach K. "Improving primary care for patients with Chronic Illness" JAMA 2002; 288: 1775-9; p. 1776.

[22] Bodenheimer T, Wagner EH, Grumbach K. "Improving primary care for patients with Chronic Illness" JAMA 2002; 288: 1775-9; p. 1777.

[23] Bodenheimer T, Wagner EH, Grumbach K. "Improving primary care for patients with Chronic Illness" JAMA 2002; 288: 1775-9.

[24] Harris Interactive (2000). Chronic illness and care giving: survey of the general public adults with chronic conditions and caregivers. National Chronic Care Consortium [On-line].Available: http://www.nccconline.org/pdf/HarrisSurveyResults.pdf .Accessed November 4, 2008.

[25] Coleman, E. A., Smith, J. D., Frank, J. C., Eilertsen, T. B., Thiare, J. N., & Kramer, A. M.(2002). Development and testing of a measure designed to assess the quality of care transitions. *International Journal of Integrated Care, 2,* 1-9.

[26] Lorig K. "Self-Management Education: more than a nice extra." Med Care 2003; 41: 699-701.

[27] Picker Institute (1999). Continuity and transition: preparing for discharge. New Visions: ideas worth sharing. Available: http://pickerinstitute.org/documents/Discharge%20preparation.pdf. Accessed November 6, 2008.

[28] Lorig KR, Sobel DS, Stewart AL, et al. "Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization. A randomized trial." Med Care 1999;37:5-14.

[29] Lorig KR, Sobel DS, et al. "Effect of a Self-Management Program on patients with chronic disease" *Effective Clinical Practice*, November/December 2001.

[30] Bower P, Kennedy A, Reeves D, Gately C, Lee V, Rogers A. Recruitment to a trial of self care skills training in long-term health conditions: Analysis of the impact of patient attitudes and preferences. Contemporary Clinical Trials 2006 Feb;27(1):49-56.

[31] Rogers, Ann. "Background paper on the Expert Patients' Programme for NICE Expert Testimony" Found at: http://www.nice.org.uk/nicemedia/pdf/ExpertPaper1ExpertPatientProgramme.pdf. Accessed October 23, 2008.

[32] Griffiths C, Motlib J, Azard A, Ramsay J, Eldridge S, Feder G, et al. Expert Bangladeshi patients? Randomised controlled trial of a lay-led self-management programme for Bangladeshi patients with chronic disease. Br J Gen Pract 2005;55(520):831-7.

[33] Kennedy A, Rogers A, Gately C. From patients to providers: prospects for self-care skills trainers in the National Health Service. Health and Social Care in the Community. 2005;13(5):431-40.

[34] Kennedy A, Rogers A, Crossley M. Participation, Roles, and the Dynamics of Change in a Group-

---

Delivered Self-Management Course for People Living With HIV. Qual Health Res. 2007 Jul 1;17(6):744-58.

[35] Southwestern Ontario Regional Partnership Leadership Forum. "System Transformation and Key Enablers and Integration Strategies" Fall 2006. Found at: http://www.lhsc.on.ca/isan/communication/comp_proj/sworp/2006_Pres/SWO_RegPrnrshp_news_Fall06.pdf . Accessed October 24, 2008

[36] Southwestern Ontario Regional Partnership Leadership Forum. "System Transformation and Key Enablers and Integration Strategies" Fall 2006. Found at: http://www.lhsc.on.ca/isan/communication/comp_proj/sworp/2006_Pres/SWO_RegPrnrshp_news_Fall06.pdf . Accessed October 24, 2008

[37] Canadian Diabetes Association "Leading Initiatives in the prevention of the complications of diabetes" National Policy Summit on the seriousness of complications of Diabetes in Canada. Found at: http://www.diabetes.ca/Files/nationapolicysummit/Materials/Leading-initiatives-in-prevention-of-DC.pdf . Accessed October 24, 2008.

[38] Canadian Diabetes Association "Leading Initiatives in the prevention of the complications of diabetes" National Policy Summit on the seriousness of complications of Diabetes in Canada. Found at: http://www.diabetes.ca/Files/nationapolicysummit/Materials/Leading-initiatives-in-prevention-of-DC.pdf . Accessed October 24, 2008.

[39] Nasmith, Louise et al. "The Challenge of Promoting Integration: Conceptualization, Implementation, and assessment of a pilot care delivery model" Relationship of the process of primary care to health outcomes: Vol. 36 No. 1 January 2004.

[40] Bergman H, Beland F, Contandriopoulos AP, et al. "Care for Canada's frail elderly population: fragmentation or integration?" Can MedAssoc J 1997;157(8):1116-21.

[41] Peter Drucker Award: Latin American diabetes Program Found at: http://www.innovation-award.ca/storya5dd.html?IdeabookID=746. Accessed October 31, 2008.

[42] Case Study of a Systems Approach to Chronic Disease Prevention and Management: The Latin American Diabetes Program of the London Intercommunity Health Centre, London,Ontario.

[43] Case Study of a Systems Approach to Chronic Disease Prevention and Management: The Latin American Diabetes Program of the London Intercommunity Health Centre, London,Ontario. P.1

[44] Case Study of a Systems Approach to Chronic Disease Prevention and Management: The Latin American Diabetes Program of the London Intercommunity Health Centre, London,Ontario. P.2

[45] Case Study of a Systems Approach to Chronic Disease Prevention and Management: The Latin American Diabetes Program of the London Intercommunity Health Centre, London,Ontario. P.3

[46] Case Study of a Systems Approach to Chronic Disease Prevention and Management: The Latin American Diabetes Program of the London Intercommunity Health Centre, London,Ontario. P4

[47] Canadian Diabetes Association "Leading Initiatives in the prevention of the complications of diabetes" National Policy Summit on the seriousness of complications of Diabetes in Canada. Found at: http://www.diabetes.ca/Files/nationapolicysummit/Materials/Leading-initiatives-in-prevention-of-DC.pdf Accessed November 10, 2008

[48] Hamilton, N., and T. Bhatti. 1996. *Population Health Promotion: An Integrated Model of Population Health and Health Promotion*. Ottawa: Health Canada.

---

[49] Barr, Victoria J. et al. *The Expanded Chronic Care Model: An Integration of concepts and Strategies from population health promotion and the chronic care model.* Found at: http://www.health.gov.bc.ca/phc/pdf/eccm_article.pdf. Accessed on November 4, 2008.

[50] Public Health Agency of Canada. Des Meules, M. (2005). Toward a Canadian Best Practices System for Chronic Disease Prevention and Control. Presented at *Best Practices for Better Health, 6th IUHPE European Conference*, Stockholm, June 3, 2005.

[51] Barr, V., S. Robinson, B. Marin-Link, L. Underhill, A. Dotts, D. Ravensdale, and S. Salivaras. "Ethe Expanded Chronic Care Model: An integration of concepts and strategies from Population Health Promotion and the Chronic Care Model." *Hospital Quarterly*. 2003; 7(1): 73-82.

[52] Barr, V., S. Robinson, B. Marin-Link, L. Underhill, A. Dotts, D. Ravensdale, and S. Salivaras. "Ethe Expanded Chronic Care Model: An integration of concepts and strategies from Population Health Promotion and the Chronic Care Model." *Hospital Quarterly*. 2003; 7(1): 73-82. (p. 76).

[53] A Framework for a Provincial Chronic Disease Prevention Initiative. British Columbia: Population Health and Wellness, Ministry of Health Planning; 2003.

[54] Salonen, Jukka T.(1991). Prevention of Coronary Heart Disease in Finland—Application of the Population Strategy', Annals of Medicine,23:6,607—612. P. 608

[55] Salonen, Jukka T.(1991). Prevention of Coronary Heart Disease in Finland—Application of the Population Strategy', Annals of Medicine,23:6,607—612 .P. 607

[56] Puska, Pekka. *The North Karelia Project: Pioneering Work to Improve National Public Health.* National Public Health Institute. Found at: http://www.ktl.fi/attachments/english/organization/ppuska/northkareliaprojectarticle . Df. Accessed November 20, 2008.

[57] Puska, Pekka. *The North Karelia Project: Pioneering Work to Improve National Public Health.* National Public Health Institute. Found at: http://www.ktl.fi/attachments/english/organization/ppuska/northkareliaprojectarticle . Df. Accessed November 20, 2008. P.3(6)

[58] Davies, M. 2008. "Commentary: Jönköping County Council." *High Performing Healthcare Systems: Delivering Quality by Design*. 145-150. Toronto: Longwoods Publishing.

[59] Baker, G.R., A. MacIntosh-Murray, C. Porcellato, L. Dionne, K. Stelmacovich and K. Born. 2008. "Jönköping County Council." *High Performing Healthcare Systems: Delivering Quality by Design*. 121-144. Toronto: Longwoods Publishing.

[60] Institute for Healthcare Improvement. nd b. *Improving Patient Flow: The Esther Project in Sweden.* Cambridge, MA: Author. Found at:http://www.ihi.org/IHI/Topics/Flow/PatientFlow/ImprovementStories/ImprovingPatientFlow TheEstherProjectinSweden.htm. Accessed November 14, 2008.

[61] Baker, G.R., A. MacIntosh-Murray, C. Porcellato, L. Dionne, K. Stelmacovich and K. Born. 2008. "Jönköping County Council." *High Performing Healthcare Systems: Delivering Quality by Design*. 121-144. Toronto: Longwoods Publishing.

[62] Baker, G.R., A. MacIntosh-Murray, C. Porcellato, L. Dionne, K. Stelmacovich and K. Born. 2008. "Jönköping County Council." *High Performing Healthcare Systems: Delivering Quality by Design*. 121-144. Toronto: Longwoods Publishing.

---

[63] Institute for Healthcare Improvement. nd a. *Charting the Way to Greater Success: Pursuing Perfection in Sweden.* Cambridge, MA: Author. Retrieved December 14, 2006. Found at:http://www.ihi.org/IHI/Topics/Improvement/ImprovementMethods/ImprovementStores/ChartingtheWaytoGreaterSuccess PursuingPerfectioninSweden.htm . Accessed November 11, 2008.

[64] Ministry of Health. "Care Plus: an overview." Wellington, New Zealand: Ministry of Health; 2004.

[65] CBG Health Research Corporation. *Review of the Care Plus Programm August 22, 2006.* Wellington, New Zealand: 2008. Found at: http://www.moh.govt.nz .

[66] World Health Organisation. The World Health Report 2000. Health systems improving performance. Geneva: WHO, 2000.

[67] Struber, Janet. "Reorienting Health Services in remote Queensland to better address Indigenous Health" Queensland Health. Found at: http://www.abc.net.au/rural/events/ruralhealth/2005/papers/reorientingservices.pdf. Accessed November 11, 2008.

[68] Struber, Janet. "Reorienting Health Services in remote Queensland to better address Indigenous Health" Queensland Health. Found at: http://www.abc.net.au/rural/events/ruralhealth/2005/papers/reorientingservices.pdf. Accessed November 11, 2008. P.1.

[69] Australian Bureau of Statistics, Australian Institute of Health and Welfare. *The Health and Welfare of Australia's Aboriginal and Torres Strait Islander Peoples*. Canberra: Commonwealth of Australia; 2005.

[70] Ibid. Zwar. P. 60. Australian Bureau of Statistics, Australian Institute of Health and Welfare. The Health andWelfare of Australia's Aboriginal and Torres Strait Islander Peoples. Canberra: Commonwealth of Australia; 2005.

[71] Si D, Bailie R, Connors C, Dowden M, Stewart A, Robinson G, et al. Assessing health centre systems for guiding improvement in diabetes care. BMC Health Serv Res 2005;5(56).

[72] Ibid. Zwar P. 60. Hoy WE, Kondalsamy-Chennakesavan SN, Nicol JL. Clinical outcomes associated with changes in a chronic disease treatment program in an Australian Aboriginal community.Medical Journal of Australia 2005;183(6):305-9. Simmons D. Impact of an integrated approach to diabetes care at the Rumbalara Aboriginal Health Service. Internal Medicine Journal 2003;33(12):581-585.

[73] Andrews B, Simmons P, Long I, Wilson R. Identifying and overcoming the barriers ot Aboriginal access to general practitioner services in rural New South Wales. Aust. J. Rural Health 2002;10:196–201.

[74] Collins J. Eyre Peninsula Chronic Disease Self Management Project for Aboriginal Communities in Ceduna / Koonibba and Port Lincoln, Report to South Australian Department of Human Services: Eyre Peninsula Division of General Practice, South Australia; 2003 Retrieved June 2005.

[75] Hoy WE, Kondalsamy-Chennakesavan SN, Nicol JL. Clinical outcomes associated with changes in a chronic disease treatment program in an Australian Aboriginal community. Medical Journal of Australia 2005;183(6):305-9.

---

[76] Zwar, Nicholas et al. "APHCRI: Stream four: A systematic review of chronic disease management" Australian Primary Health Care Research Institute. September 2006.

[77] Suter et al. Health System Integration- Definitions, Processes and Impact: A Research Synthesis Found at:

http://www.calgaryhealthregion.ca/hswru/documents/reports/HEALTH%20SYSTEMS%20INTEGRATION_2007.pdf Accessed on November 11, 2008.

[78] Ibid.

[79] Spragins, Wendy A., Lorenzetti, Diana L. " Public expectation and Patient experience of integration of health care: A Literature Review" Change Foundation. June 2008

[80] Harris Interactive (2005). "2005 Commonwealth Fund international health policy survey of sicker adults." New York NY: Harris Interactive.

[81] Health Council of Canada (2008). "Canadian survey of experiences with primary health care in 2007: a data supplement to Fixing the foundation: an update on primary health care and home care renewal in Canada." Toronto ON: Health Council of Canada.

[82] Health Council of Canada (2008). "Canadian survey of experiences with primary health care in 2007: a data supplement to Fixing the foundation: an update on primary health care and home care renewal in Canada." Toronto ON: Health Council of Canada.

[83] Romanow, Roy J. "Commission on the Future of Health Care: Building on Values: The Future of Health Care in Canada" 2002 Found at: http://www.hc-sc.gc.ca/hcssss/alt_formats/hpb-dgps/pdf/hhr/romanow-eng.pdf Accessed on November 11, 2008.

[84] Ontario Chronic Disease Prevention Alliance. *Thinking like a system: the way forward toprevent chronic disease in Ontario.* March 2006.Found at: http://www.ocdpa.on.ca/docs/SystemPlan2005_06FinalJune2006.pdf Accessed on October 22, 2008.

[85] Barr. Victoria J. et al. "The Expanded Chronic Care Model: An Integration of Concepts And Strategies from Population Health Promotion and the Chronic Care Model" Healthcare Quarterly. 7 (1) 2003 73-82. Found at:

http://www.health.gov.bc.ca/phc/pdf/eccm_article.pdf Accessed on: October 21, 2008.

[86] Lyons, Christine and Anne-Marie Kungl "Ontario Chronic Disease Prevention Alliance: Environmental Scan and Collaborative Alliance Efforts Project" (2005) Found at:

http://www.opha.on.ca/activities/conference/2005/Session_5F/C_Lyons5F.pps.

Accessed on November 10, 2008.

[87] The Ontario Chronic Disease Prevention Alliance "Thinking like a system: the way forward to prevent chronic disease in Ontario" March 2006. Found at:

http://www.ocdpa.on.ca/docs/SystemPlan2005_06FinalJune2006.pdf

---

Accessed on November 13, 2008.

[88] Bains, N., K. Dall, and J. Hohenadel. (2007). *Chronic Conditions in the North West LHIN. Health System Intelligence Project (HSIP) Report.* Toronto, ON: Ministry of Health and Long-Term Care. (p. 4).

[89] Bains, N., K. Dall, and J. Hohenadel. (2007). *Chronic Conditions in the North West LHIN. Health System Intelligence Project (HSIP) Report.* Toronto, ON: Ministry of Health and Long-Term Care. (p. 5).

[90] Bains, N., K. Dall, and J. Hohenadel. (2007). *Chronic Conditions in the North West LHIN. Health System Intelligence Project (HSIP) Report.* Toronto, ON: Ministry of Health and Long-Term Care. (p. 9, 11, 13, 15, 17, 19, 21, 23, 25).

[91] Bains, N., K. Dall, and J. Hohenadel. (2007). *Chronic Conditions in the North West LHIN. Health System Intelligence Project (HSIP) Report.* Toronto, ON: Ministry of Health and Long-Term Care. (p. 27).

[92] Bains, N., K. Dall, and J. Hohenadel. (2007). *Chronic Conditions in the North West LHIN. Health System Intelligence Project (HSIP) Report.* Toronto, ON: Ministry of Health and Long-Term Care. (p. 32).