



Winnipeg Regional Health Authority Office régional de la santé de Winnipeg
Caring for Health À l'écoute de notre santé

“Chronic Disease: Access to Health Care and Barriers to Self-Management”



(Summary version of report)

Community Health Advisory Councils January 2010

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Preface

This report contains the issues and ideas generated by the Community Health Advisory Councils over the course of 2 meetings held from September to December 2009.

The Councils were asked by the Winnipeg Regional Health Authority's Board to explore how people living with chronic disease access the health system and the barriers that they face in managing their condition. This report will be shared with the WRHA Chronic Disease Collaborative, Program and Community Teams, Community Health Agencies, and other community organizations across the health region.

The Report includes:

- An overview of the methodology, discussions about chronic disease, issues and ideas relating to accessing health care when you have a chronic disease, and an exploration of the barriers individuals face managing their chronic disease and ideas for how individuals and the health care system can address these barriers.
- Please refer to the full report for discussion notes from the Councils

Appendix A provides a table of Priority Barriers to the Self-Management of Chronic Disease

Appendix B provides a map of the Winnipeg health region's community areas.

Appendix C provides lists of Council members, Board liaisons, and staff that support the work of the Councils.

It is hoped that report will be useful to the WRHA Board, the WRHA Chronic Disease Collaborative, Program and Community Teams, funded agencies of the Winnipeg Regional Health Authority, and community organizations working to improve how people with chronic disease access health care and overcome barriers to managing their chronic disease.

Table of Contents

	<u>Page</u>
Executive Summary	4
I Report Summary	9
Introduction and Methodology	11
What is Chronic Disease?	
Accessing Primary Care when you have a Chronic Disease	12
Ideas for Improving Access to Primary Care	13
Who should be part of the Chronic Disease Care Team?	16
Considerations for Vulnerable Populations	18
Barriers to the Self-Management of Chronic Disease	20
Ideas for Addressing Priority Barriers to Self-Management of Chronic Disease	21
 Appendices	
 Appendix A	 34
Table of Priority Barriers to the Self Management of Chronic Disease	
 Appendix B	 37
Map of the Community Areas in the Winnipeg Health Region	
 Appendix C	
Acknowledgements	39

Executive Summary

During the Community Health Advisory Councils' exploration of chronic disease, Council members shared their personal experiences living with chronic disease, some had multiple chronic diseases. Others shared their experience as family members or friends. They all spoke of the tremendous toll that chronic disease takes on people and their families and of its impact on one's mental health and of their ability to continue to work.

The Councils agreed that the ultimate goal for those living with chronic disease and for those providing care and support, should be to increase the periods of wellness, decrease the periods of extreme illness, and maintain quality of life for as long as possible. Many things need to be in place for this to be realized: access to and a supportive relationship with primary care providers (like family doctors and nurse practitioners), counsellors, specialists, nutritionists, health educators, and others; support and advocacy; and the acknowledgement that some may face barriers to managing their condition and will need support to address them.

"Some people may come up against all of these barriers and kind of give up. It takes a lot of work and effort to manage a chronic disease." Downtown and Point Douglas Council member

Some of the key observations and suggestions that Council members came up with over the course of their discussions were:

- The absolute importance of having a family doctor or other primary care provider (like a nurse practitioner) when you have a chronic disease in order to gain access to specialists and other resources;

"It is not okay to not have a doctor. This becomes critical when you have a chronic disease." St Boniface and St Vital Council member

- The need to address the issue that some family doctors are not accepting people with chronic disease as new patients;
- The need to review how fee-for-service physicians are paid - one issue per 10 minute appointment and how that negatively impacts on the ability

to provide care for patients with chronic disease, who face multiple health issues;

- The importance of engaging the patient in their treatment plan and ensuring that they have support and someone to advocate and help them navigate the system if they require it; and,
- The need for a holistic approach to providing care that includes a team to address the physical, social, mental, and spiritual aspects of managing a chronic disease.

Council members provided input about what special considerations for care should be made and addressed for vulnerable populations. Some of the issues that were identified include: difficulty getting to appointments and navigating the system; literacy and language barriers; not understanding their chronic disease; lack of child care for single parents who need to go to appointments; financial issues; lack of support and advocacy; and those with mental health issues and/or addictions issues.

As important as acknowledging the barriers that many people living with chronic disease face in being able to self-manage and stay as healthy as possible is the work to address these barriers.

"We need to educate professionals about the barriers that patients may face, to see life from the patient's perspective. The doctor's job is to focus on that patient and where they're at in coping with the chronic disease." River East and Transcona Council member

All of the Councils identified low income and poverty as having a direct impact on an individual's ability to self-manage chronic disease. Managing a chronic disease is expensive. The lower the income someone has, the less able they are to find a solution, access programs, get to appointments, access prescriptions, and stay well. To begin to address this barrier, Councils felt that the WRHA needs to explore the relationship between income and health in partnership with other government departments and community organizations and develop collaborative solutions.

The barriers that the Councils identified as priorities for the health region were:

- Lack of awareness of and access to health care services and resources
- Lack of primary care providers, good relationship to primary care providers, and the lack of an integrated approach to care (includes: poor communication between health care providers and with patient and family)
- Lack of support and advocacy
- Mental health issues
- Language and Cultural Barriers

Some of their key suggestions to addressing these barriers include:

Lack of awareness of and access to health care services and resources

- Have chronic disease resources bookmarked on the WRHA website that are legitimate and reliable.
- Provide home visits for house-bound people. Go to the patient in their home. This helps care providers better understand the context of the patient's situation, teach self-care, and will enable them to get a better sense of the patient's barriers to self-management.

Lack of primary care providers, good relationships with primary care providers, and a lack of an integrated approach to care

- Need for more doctors, nurse practitioners, and alternative health care providers who can spend more time developing relationship with patients as part of the health care team.
- Need central information point - on-line - that lists all resources for people with chronic disease, support groups, who to contact, etc.

Lack of support and advocacy

- At appointment when a chronic disease diagnosis is shared with a patient, the health care provider needs to determine the patient's ability to follow-through on treatment plan and to navigate the system. If they are unable to, they need to ensure there are family members or friends to provide support and advocacy. For those without, external advocates need to be brought in.

- WRHA should be linking with chronic disease associations and encouraging patients and family members/friends to use these organizations for information and support.

Mental health issues

- Develop support groups for different chronic diseases. They need to be accessible (for those who work during the day) so that people can listen to others going through the same issues, experiences, thoughts, etc. regarding their condition.

Language and Cultural Barriers

- Outreach workers to accompany Newcomers to doctors' appointments. Ensure that they can deal with cultural differences and help them navigate the health system and advocate for them.
- Have information on chronic diseases and treatment options and self-management strategies, etc. available in a variety of languages in written format and on WRHA website.

Section I

Report Summary

Introduction and Methodology

Priority Issues and the Community Health Advisory Councils

In September 2009, the Board of the Winnipeg Regional Health Authority (WRHA) asked the Community Health Advisory Councils (CHAC's) to explore issues related to how people with chronic disease access primary care and what barriers these individuals face when attempting to manage their chronic disease. This report will advise the Board and will be utilized by the WRHA Chronic Disease Collaborative and WRHA Program and Community Teams. The role of the health advisory councils is to provide community perspectives and suggestions to issues that are a priority to the Winnipeg Regional Health Authority.

Population Health Framework and Perspectives from their community

The Community Health Advisory Councils use a population health framework when exploring health issues - taking into consideration the social, environmental, economic, and other factors that impact the health of a population. A population health approach helps identify factors that influence health, to analyze them, and to weigh their overall impact on our health.

The Meetings

At the first meetings of the Councils, they began their exploration of chronic disease by brainstorming what chronic disease means to them. Many of the Council members were living with chronic disease and were able to share what the experience meant to them, to their families. Others had family members or friends with chronic disease. It seemed that almost all of the over 80 volunteers who participate on the Community Health Advisory Councils had direct experience with the topic.

A common understanding of "chronic disease" was arrived at with examples of chronic diseases. This set the tone for the following questions:

- How do people living with chronic disease access care?
- Who could deliver care and why would they be important to have on the chronic disease care team?
- What special considerations need to be addressed in providing care for vulnerable populations in your community?

At the second set of meetings, Council members were asked to respond to the following question:

- From your perspective, what are some of the barriers that people living with chronic disease face in managing their condition?

Members participated in a prioritization exercise allotting points (3 points for their #1 barrier, 2 points for their #2 barrier, and 1 point for their #3 barrier) to the three barriers that they felt impacted most on an individual's ability to self-manage a chronic disease. The points were added up and the three (sometimes four) top priority barriers to self-management were identified. Council members spent the remaining time of the meeting sharing suggestions for how these barriers could be addressed by the WRHA and others.

Presentation to the Board of the Winnipeg Regional Health Authority

Discussions from the meetings of all six Community Health Advisory Councils were then compiled into this report. Chairs and Vice Chairs of the Councils presented this report to the Board of the Winnipeg Regional Health Authority in January 2010.

What is Chronic Disease?

The first set of meetings began with the question, "what is chronic disease?" It was important to ensure that Council members had an opportunity to develop a unified understanding of the concept and to begin to share their own experiences of living with a chronic disease or the experience of being a family member or friend of someone with a chronic disease. All of the Councils felt that there was a lack of understanding by the greater public or society about what chronic disease is and how serious it is. All of the Councils stressed the importance of conducting an information campaign to increase public awareness of chronic disease.

Councils described chronic disease as "an on-going illness that is incurable but manageable". For people living with chronic disease, there are periods of wellness and periods of illness with acute, debilitating symptoms. For those who manage their condition well, they can stay relatively healthy and maximize their quality of life.

All Councils pointed to the mental health and psycho-social aspects of living with a chronic disease. Many also included mental health conditions such as depression, schizophrenia, and bi-polar illness as being chronic in nature and important to include when exploring chronic disease issues. The implications for those living with chronic disease can include depression, feelings of hopelessness, anger, and anxiety.

"If you can live with a degree of hope, then you can live with it, adapt. It is incurable; there's finality to it." Member of the River Heights/Fort Garry Council

Councils also discussed **the impact on family and friends**, and the significance of their role in supporting an individual with chronic disease. Council members also identified how people with lower incomes are more impacted by chronic disease and face more barriers to managing their condition and staying healthy. They were asked to brainstorm a list of chronic diseases, which could be physical or mental. Their list included -- auto-immune disorders, multiple sclerosis, arthritis, asthma, cancer, Parkinson's Disease, macular degeneration, fibro-myalgia, lupus, diabetes, epilepsy, and heart disease and stroke.

Access to primary care when you have a chronic disease

When Council members were asked to describe how people with chronic disease access the health system, they shared many underlying problems that they felt currently exist and recommendations to make it easier to access care and to improve how care to patients with chronic disease is delivered. Council members felt that the health care system is geared for dealing with acute health issues and that people with chronic disease don't get adequate attention.

Underlying problems with how primary care is currently delivered:

Councils pointed to a number of underlying problems with how primary care is set up that makes it almost impossible for people with chronic conditions to receive adequate care.

- **Shortage of family doctors.** If you don't have a family doctor, how do you get primary care?
- Family doctors who are **not accepting new patients with chronic disease** conditions (interviewing them first and then denying them care)
- Fee for service family doctors run their practice as a business and **Manitoba Health policies on payment to family doctors specify that doctors can only see a patient for one issue at a time** for under ten minutes, which does not meet the needs of someone with chronic disease who may need to have multiple issues dealt with during an appointment with their doctor.
- **Walk-in clinics** - many people with chronic disease are patients of walk-in clinic physicians where continuity of care is compromised and there is little relationship between doctor and patient. Patients also must see physicians at walk-in clinics 3 separate times in order to get a referral to a specialist.
- If you have a **crisis with your chronic disease, you often get referred to emergency** because your family doctor can not see you immediately.
- The **referral process to specialists** can cause bottlenecks and can be lengthy.

- Need to look at **cultural and belief systems**. People need to take more responsibility for their own health and be active in their own care and treatment of their chronic disease.
- **Vulnerable populations** don't know how the health system works and are the least likely to be able to access primary care when they need it.

Ideas for how to improve access to primary care:

The most important improvement is to ensure that people living with chronic disease have **access to primary care whether that is through a family doctor or a nurse practitioner**. Continuity of care will follow. Councils also stressed the importance of a having a good relationship with their primary care provider. Many Councils discussed the possibility of prioritizing people with chronic disease when there are openings for new patients at family physicians offices or community health clinics. Access to primary care is essential in order to access the range of services, specialists, and referrals to health and community-based resources.

Need for appointment structure that meets needs of chronic disease patients

- Develop a different way to schedule appointments - keeping openings so that if you need to see your primary care provider because your condition has worsened you can get in the same day or next day
- Start at "frontline" in physicians' offices and community health clinics. Have receptionists made aware of chronic disease patients and prioritize them for quick appointments sooner.
- Provide the option for over the phone consultation with nurse practitioners.
- Keep a number of appointments open every day at physicians' offices and clinics for urgent care that can be triaged over the phone that would otherwise have to go to emergency.
- Schedule regular monthly or bi-monthly appointments for patients with a chronic disease - to keep them well, maintain health, sometimes may need urgent care if their condition worsens, explain to them why they need these appointments

Address how Family Physicians are paid, fee-for-service issues, and other funding issues

Council members feel that it is important to change the "one issue per visit" practice so that patients with chronic disease can have multiple issues dealt with.

- Have a certain amount of health care funding directed towards Family Practitioners addressing prevention issues and treating patients with chronic conditions.
- Create incentives for Family doctors to accept people with chronic diseases as new patients.
- Funding could be directed towards increasing the numbers of nurse practitioners and physician assistants to assist family doctors.
- Link between the WRHA and doctors is very important; they must work together.
- There are also salaried physicians who work for community health agencies and WRHA primary care clinics and some who receive a combination of fee for service/incentives and salary. They can see patients for multiple issues and for longer periods of time and aren't as limited as fee for service in how they can provide care. This should be further explored and expanded.
- Physicians and other primary care providers should be paid for over the phone and faxed communications with patients. This process could be created to allow chronic patients to connect with doctors about some issues of their care.
- Doctors should be able to bill for extra time for longer initial appointment with patient to discuss the chronic disease, treatment options and plan, etc.
 - o Physicians need to be able to show that their patients are having good outcomes
 - o Performance based fee for service outcomes

Dealing with referral bottlenecks and lengthy waits

- Develop alternative to referral system - short-track referrals so that once someone has been referred to a specialist they don't have to go back to their physician in order to see them again (once a diagnosis has been confirmed).

Providing urgent care when chronic disease condition worsens

Because of the episodic nature of chronic disease and the potential to become very ill very quickly, chronic disease patients need special services to access care. People living with chronic diseases are most stressed at night. There should be some way to contact primary care or get feedback from a physician, other than visiting emergency department.

Role of individual in managing their chronic disease:

Councils felt it was important that people with chronic disease play an active role in managing their condition and be engaged in their treatment plan. There is a level of personal responsibility when one has a chronic disease in terms of accessing the care that one needs. They need to make doctor's appointments effective; go prepared, write down what's happening with you and any questions you have for the doctor.

Special approach to chronic disease patients:

Council members provided suggestions for how to approach patients with chronic disease, what their needs are at various stages of their illness.

- Begin with assessment, then build care plan - are they able to manage own care? If not, ensure there are family supports or bring in an outside advocate to help them.
- At diagnosis, have mental health clinician help patients process information and come up with plan to stay mentally well.
- Need to consider that it will be difficult for people who get really ill to access their regular care. Develop special plan to address this.

Who delivers care and why they would be important to have on a chronic disease care team?

Members of the Councils were asked for their input about who could provide care to people with chronic disease. Overall, they supported a **multi-disciplinary approach that “addresses the physical and mental components of a chronic disease.”** There was a consensus that currently there was too much reliance on doctors to provide all of the needs of patients with chronic disease. At the same time, Councils recognized the shortage of physicians and the issue that a number of physicians were not taking patients with chronic disease. **The expanded use of nurse practitioners and physicians’ assistants** was encouraged by all Councils, in providing care to people with chronic disease conditions.

Many people pointed to the existence of some clinics that have been developed to provide care to either children or adults with some chronic diseases - such as diabetes (children) and arthritis. There was unanimous support for a **team and potentially clinic-based approach to providing care. Monthly clinics for different chronic diseases could be held at Access Centres.** Doctors or nurse practitioners could lead the clinics and they could also include the following health and health-related professionals: social worker or counsellor, nutritionist, physiotherapist, occupational therapist, pharmacist, health educator, and recreation specialist. Specialists like endocrinologists for a diabetes clinic, could also provide services. Council members stressed the importance of having a mental health clinician, social worker, or counsellor available to provide support before depression and anxiety set in. A number of Councils identified naturopaths, chiropractors, massage therapists, and pain management experts as other potential team members. Council members also suggested the importance of physically locating the team together for the clinic and of linking with chronic disease associations for their participation. These clinics would utilize best practices and be promoted on the WRHA website

Some of the Councils brought up the **“shared care” model in which a counsellor is linked to family doctor practices** to assist with mental health issues of patients. Council members felt that this model could be used with nurse practitioners, counsellors, and others to support family doctors in providing care for patients with chronic disease. Given the difficulty in

finding the resources to develop clinics for every chronic disease this approach may be more practical. In either approach, Council members recommended the use of case managers (who could coordinate treatment/care), especially for those who were vulnerable and lacked support and advocacy from family and/or friends. They also felt it was extremely **important for family and/or friends to be included** so that they could better support and be better informed about the condition and treatment options.

The Councils were unanimous in their recommendation that the WRHA programs **partner or link up with chronic disease associations** so that they can increase the awareness of these organizations and their usage for advocacy and educational purposes. There was agreement that **peer support and mentoring is an extremely important part of the approach** to providing care and engaging people with chronic diseases. Council members also felt that there were potential roles for volunteers to support and advocate for person with chronic disease, assist with appointments, etc., and the development of chronic disease support groups where people with the same chronic condition can support and encourage one another in the management of their chronic disease.

"It is important to teach, enable, encourage, and support people so that they can manage their chronic disease. A peer mentor is someone who could check-in with you periodically so that you could provide an update on your physical and mental status. They can enable you, as someone who successfully manages their own condition." Downtown and Point Douglas Council members

That members of the chronic disease care team be culturally relevant and responsive was an aspect of the team approach that was important to Council members. Chronic care teams should include members who are Aboriginal and immigrants and Newcomers who may have received training in their country of origin. These team members can provide additional support and connect with chronic disease patients.

"Newcomers who are former doctors and nurses, could play a critical role as part of the health care team, could help with home visits, etc." Downtown and Point Douglas Council member

Considerations for vulnerable populations

Councils were also asked to think about what special considerations need to be made for vulnerable populations living in their communities to improve their opportunities to access health care for their chronic condition. They began by coming up with a list of populations they felt were most vulnerable both to getting a chronic disease and to not being able to access primary care and manage the condition on their own.

“Those living with chronic disease are vulnerable (as a result of) just having a condition, as multiple issues create barriers for being able to access primary care (one issue per visit)” St Boniface and St Vital Council member

Populations that the Councils considered vulnerable:

- Elderly/Seniors
- Those with reduced mobility/access - like people with disabilities
- People with mental health issues
- Single parents
- Newcomers and Immigrants -- who do not speak English/French experiencing language and potentially cultural barriers
- Deaf community
- People who can not manage their own chronic disease and can not navigate the medical system who do not have support from family or friends
- People from isolated and/or Northern communities who come to Winnipeg for care
- People who do not have financial resources
- Homeless population
- Those with substance abuse issues
- Those who do not have access to transportation
- Those who do not have phones
- Those living in fear - neighbourhoods are not safe, afraid to leave their homes
- Those who have difficulty keeping appointments

Issues faced by vulnerable populations:

Councils members then considered issues that vulnerable populations would face in accessing health care and managing their chronic disease.

- Access and ability to go to appointments
- Communication issues - literacy, language barriers
- Lack of child care so that they can go to appointments, etc.
- Financial issues - to afford medications, nutritious food, transportation, medical equipment, programs in the community
- Lack of advocacy and support
- Lack of understanding and being able to navigate the health system
- Lack of access to information about their chronic disease
- People with issues that make it difficult for them to access the system and receive care - mental health issues, substance abuse issues

Vulnerable populations may need:

- Doctors and other primary care providers to determine their ability to manage their condition and navigate the system;
- Mental health support;
- Financial assistance to cover prescription costs, transportation, buying nutritious groceries, accessing community programs;
- Help getting to appointments - transportation, help paying for child care;
- To be able to talk to someone in their own language, who understands their culture;
- Advocates for those who need support to manage their disease - a helping hand to assist with coordination of care and to navigate the health system;
- Communication in a variety of languages in plain, simple language;
- Good information about chronic diseases, the individual's role in managing it, treatment, and what happens if treatment plan is not followed; and,
- Care at home if they are house-bound.

Barriers to self-management of chronic disease and ideas for how to address

At the second set of meetings, the Councils brainstormed barriers that people living with chronic disease face in managing their condition. Barriers were categorized into themes and Council members voted on the barriers they felt were the most significant to self-management of chronic disease.

The priority barriers for all of the Councils were reviewed and those identified as priorities for most or all of the Councils are listed below and also in a table format. (See Appendix A) An important suggestion that came out of the discussions regarding barriers was that primary care providers - doctors and nurses - should conduct an assessment of the barriers that newly diagnosed individuals face in managing their condition. A plan then should be developed with the individual of how these barriers will be addressed.

Barriers prioritized by Councils:

1. Lack of awareness of and access to health care services and resources
2. Lack of primary care providers, good relationships with primary care providers, and lack of an integrated approach to care (includes: poor communication between health care provider and patient and family)
3. Lack of support and advocacy
3. Mental health issues
4. Language and Cultural Barriers
5. Low Income/Poverty

This section includes input from the Councils on the priority barriers to self-management of chronic disease and suggestions on how these barriers could be addressed by the WRHA and others. It is important to note here that all of the Councils identified low income and/or poverty as the most significant barrier that people face in managing their condition. Many of the Councils felt that given the WRHA could not directly address this particular barrier, they chose to focus on other barriers that the WRHA could address instead.

1. Lack of awareness of and access to health care services and resources

The most significant barrier identified by the Councils, was the lack of awareness and access to health care services and other resources. Councils also felt that many family doctors were also unaware of all resources available for their patients.

Another significant issue that some individuals may face is a **lack of health literacy** - little understanding and awareness about their health and of what is wrong with them. They will require information that is accessible about their chronic disease, the treatment options available and steps to managing their condition. Another issue involves getting reliable information. In the age of "Dr Google" and a huge number of websites, blogs, etc. about health issues, knowing what is reliable, good information is sometimes difficult and some people may choose treatment options and alternative therapies that are ineffectual and worst, a risk to their health.

For some individuals with chronic disease, **getting to appointments becomes a barrier**. They may not be able to afford transportation (which includes the cost of parking) or they have reduced mobility which makes leaving their home very difficult. **Accessing health services is dependent upon having a way into the system - typically a family doctor**. Many individuals do not have a family doctor which getting referrals to specialists and on-going, consistent care almost impossible. This issue is explored in much greater depth under the heading, "accessing primary care."



IDEAS to address:

- Provide information about chronic disease in plain, simple language. Eliminate medical jargon. Make information about prescriptions much clearer.
- Get information out to people about alternative health programs like naturopaths and traditional Aboriginal medicine.

- Health Links/Info Santé should be promoted more. Could staff provide information to people with chronic disease about services related to their chronic disease?
- Have chronic disease resources bookmarked on the WRHA website that are legitimate and reliable.
- Put information on chronic disease resources and groups in the telephone book WRHA insert
- Provide assistance with transportation to those who need it - partner with charities, volunteer driver programs, the United Way, etc.
- Taking chronic disease care into communities - into cultural and other community centres using nurses and volunteers.
- Provide home visits for house-bound individuals. Go to the patient in their home. This helps care providers better understand the context of the patient's situation, teach self-care, and will enable them to get a better sense of the patient's barriers to self-management.
- Use technology to allow greater access to care. Have Health Links/Info Santé provide advice to chronic disease patients when they have concerns about worsening condition, etc.
- Use technology for "virtual care/treatment program and management" - in which chronic disease patients have an account and can access information about their treatment program and on-line chat room with a nurse practitioner.

2. Lack of primary care providers, good relationship with primary care providers, and a lack of an integrated approach to care:

All of the Councils felt that an extremely significant barrier to the self-management of chronic disease was **not having a primary care provider, like a family doctor, that you have a good relationship with**. The Councils also pointed to a **lack of coordination of health services** related to chronic disease as well as **poor communication** between the health care provider and the individual with a chronic disease and their family and other supports.

Not having a family doctor or other primary care provider is a barrier to being able to access other important health services, including specialists. Having a chronic disease can be barrier to getting a family doctor, as many doctors are now not accepting new patients that have chronic disease.

"Our reliance on doctors, specialists and the belief that only doctors can address issues can be a barrier to accessing primary care through alternative professionals, like nurse practitioners. This is an attitude we should let go of. The doctor can consult, but we can use other health professionals and resources to address issues related to our chronic disease." St James and Assiniboine South Council member

Many people have access to primary care, but no potential to build a **long term relationship with their health care provider**, like those who only have access to walk-in clinics for their primary care. This has a huge impact on the continuity of their care, and on the potential for success with their treatment plan and the on-going self-management of their chronic disease. This can impact a primary care provider's ability to help with insurance and medical leave processes. Walk-in doctors do not develop long term relationships with their patients and often do not know their patients well enough to vouch for physical and mental health issues that may require medical leave from work.

Council members felt that a **lack of trust, empathy, understanding of patient's barriers**, and attitude of "caring " instead of "supporting" them, also impacts people's ability to self-manage their condition. Many Council members mentioned the shortcomings of many family doctors and specialists regarding their "bedside manner" and of the patient's need for physicians to understand the barriers that patients face, be sensitive to them, and the importance of drawing out information from them during appointments.

Councils also identified **communication barriers between health care providers and patients** as impacting self-management and the successful follow through on treatment plan. Many patients are afraid to ask questions when they don't understand or might be embarrassed to disclose symptoms. Health care providers should be able to provide information on a level that the patient can understand. Some patients may feel that no one listens, especially to the elderly.

"Some patients may not have the right words, ability to describe accurately what they are experiencing - body, mind, and spirit. They don't have the vocabulary and may have memory issues. They might not be taken seriously or be accurately diagnosed as a result." Seven Oaks and Inkster Council member

The lack of coordination or fragmentation of services creates barriers for individuals who may have many appointments but need to go all over the city to receive services. Patients may require care and support from other specialists (like occupational therapists) but their care isn't integrated, so they don't receive it. The referral process also creates problems for patients who have to go repeatedly back to family doctor for referrals to specialists like dieticians. Council members also highlighted the need for the electronic health records to ensure information is shared between care providers and to help with the coordination and integration of their care.



IDEAS to address:

- Need for more doctors, nurse practitioners, and alternative health care providers who can spend more time developing relationship with patients as part of the health care team.
- The issue of walk-in clinics in the North End needs to be explored.
- Need to address issue of short (5 minute) appointments and how it impacts on the health care providers ability to exchange information, ask and answer questions, have quality discussion of treatment options, etc
- Need to make people aware of what patients can do for themselves - know what you need to know about your body/health/self
- Educate health care professionals about how their behaviour/ approach is experienced by patients - poor listening skills, talking down to them, not talking on the same level, not being empathetic
- Educate professionals about the barriers that patients may face/see life from the patient's perspective, the doctor's job is to focus on the patient and where they're at in coping with the chronic disease
- Physicians need to spend time with patients to build trust, a relationship
- Need central information point - on-line - that lists all resources for people with chronic disease, support groups, who to contact, etc.
- Improve the partnership between family doctors and specialists - information needs to flow back and forth - also need to agree on treatment plan
 - Need to continue to plan with family doctor - have them as the "hub" so that there can be whole person care
- Hold a public awareness campaign about the importance of asking questions of your health care providers and taking control of your chronic disease care plan.

3. Lack of support and advocacy

For those living with a chronic disease, **support and advocacy is essential to accessing health and community resources and to be able to follow through on their treatment plan.** Not having any support can jeopardize this. Council members pointed to the need for support when first someone is first diagnosed with a chronic disease. Many people shut down when they first receive a diagnosis and may go through a phase of denial. Councils all agreed on the importance of assessing an individual's ability to manage their condition and to navigate health and community services. For those who can not manage on their own, health care providers need to ensure that family or friends have the ability to support them and advocate for them. The very elderly who are dependent on family members for support to retain their quality of life are extremely vulnerable.

Many Council members identified that some people experience a lack of support, understanding, and acceptance of their chronic disease from family, friends, their employer, doctor, insurance companies, and others. Not having a supportive employer who allows time off for medical appointments, sick days, and who understands that person with a chronic disease will have really bad days from time to time, can have a tremendous negative impact on an individual with chronic disease.

All people with chronic disease experience the **challenges of motivation and sticking to their treatment plan** at some point. Changing patterns of behaviour is very difficult. Councils felt that peer support groups were instrumental in keeping people on track and reinforcing messages about how to self-manage chronic disease.

"The amount of energy it takes to be compliant with your treatment plan is incredible- diet, exercise, medication, self-monitoring, etc. It takes a lot of energy, even if you're up for it." St James and Assiniboine South Council member



IDEAS to address:

- At the appointment when a chronic disease diagnosis is shared with a patient, the health care provider needs to determine the patient's ability to follow-through on treatment plan and to navigate the system. If they are unable to, they need to ensure there are family members or friends to provide support and advocacy. For those without, external advocates need to be brought in.
- Create advocate positions to assist those without any support who need assistance/support in navigating the system and having their needs met -- Create advocate positions at the community level - (Access Centres and other WRHA Community Health and Social Services offices)
- Include family and friends in education about chronic disease, and the treatment plan and care approach.
- Develop volunteer mentors to work with patients who have chronic diseases - maybe in partnership with chronic disease associations
- Develop support groups and utilize retired health care professionals to assist with health education component
- Should be more public awareness about chronic diseases.
- WRHA should be linking with chronic disease associations and encouraging patients and family members/friends to use these organizations for information and support.
 - Doctors, nurses, etc. should refer patients and families to chronic disease associations.

3. Mental health issues

All of the Councils discussed at length the incapacitating effects of depression and anxiety on many living with chronic disease.

"Many experience the feeling of loss of control; the feeling that you are the disease." St Boniface and St Vital Council member

If not addressed, this can put an individual's treatment plan at risk. Those who are isolated, not connected to others with the same condition are especially vulnerable to the negative mental health impacts of chronic disease. For some, they may experience denial and anger and refuse to be engaged in their treatment plan.

Councils also discussed the additional barriers faced by those who have pre-existing mental health issues who then must cope with the additional stresses and challenges of managing a chronic disease. This includes individuals with addictions issues.



IDEAS to address:

- Health care providers need to help people acknowledge that learning that you have a chronic disease is a loss, but you can still have a good life, manage your illness. People need to be supported through the transition of accepting that they have a chronic disease. This needs to be the first part of their treatment plan.
- Develop support groups for different chronic diseases. They need to be accessible (for those who work during the day) so that people can listen to others going through the same issues, experiences, thoughts, etc. regarding their condition. The WRHA could work in partnership with chronic disease non-profit groups.
- People need to know that the earlier we catch symptoms, the better the chance is to stay healthier and have a better quality life with less deterioration as a result of the disease.

- People need to be ready for behaviour change. Family and friends are key to this and their support is critical.
- Include mental health counsellors/supporters as part of the team approach. Include patient's supports in peer support and overall treatment program - families and friends who can then further support them. Health care providers need to recognize how hard a chronic disease can be on the patient's family and friends.
- Should have a holistic approach - body, mind, and spirit to treatment of chronic disease - mental health, diet, exercise, stress management, and other alternative approaches.
- Need to develop approaches to treating/providing services to people with chronic disease who also have addictions issues
- Educate health care professionals about the mental health aspects of chronic disease.
- Expand the shared care model in physicians' offices to include counselling for patients with chronic disease, addressing their mental health concerns.

4. Language and Cultural Barriers

For **Newcomers with little or no English or French** and little or no understanding of our health care system, getting diagnosed with a chronic disease and getting a treatment plan to follow-through with, can be completely confusing and overwhelming, and have little chance for success.

"Language is a very big barrier for the Newcomer population. The difficulty with language makes everything else difficult. And, the health care system is so different from what many are familiar with, like how long you must wait to see a doctor. You're not able to communicate, you're ill, and the relationship with health care worker is not there, there is no continuity." Downtown and Point Douglas Council member

Not having materials about chronic diseases and treatment options makes it very difficult for many to understand their condition and what they must do to manage it. Those who go to doctors' appointments without an interpreter, they are unable to understand what the physician is asking them.

Health care providers who do not know how to work with people from different cultures and who have a lack of knowledge of culture and faith practices can have a negative impact on the doctor-patient relationship and the willingness of the patient to follow through on the treatment plan.

A couple of the Councils identified the shortage of French primary care services in the region as well.



IDEAS to address:

- Important to consider "how" we give information - and learn how different cultures would prefer to receive information and develop strategies based on this. Will need to also consider that some

- Newcomers may have decreased literacy levels and may become lost because they cannot understand.
- Outreach workers to accompany Newcomers to doctors' appointments. Ensure that they can deal with cultural differences and help them navigate the health system and advocate for them.
 - Need interpreters to be more available to accompany to appointments, and to help express feelings.
 - Develop health advocates to assist Newcomers.
 - Have special health clinics for Newcomer population.
 - Welcome Place and International Centre - could partner with them to develop health advocacy strategies, assistance with acclimatization, interpreters, etc.
 - Support for primary care physicians with interpreter services/phone line, etc.
 - Health care providers should ask people what is important to them, as part of their culture related to whatever health services they are receiving.
 - Address cultural biases within the system. Need to be aware of cultural diversity and different ways that people from different cultures communicate
 - Increase awareness of the Language Access Program - let the public know about it so they can ask for it if their health care provider does not make arrangements
 - Have cultural awareness training for staff - including information about the Language Access Program
 - Have cultural associations, faith groups, etc. hold sessions about different chronic diseases
 - Hire more doctors with diverse backgrounds - focus on Francophone
 - Have information on chronic diseases and treatment options and self-management strategies, etc. available in a variety of languages in written format and on WRHA website.
 - Engage volunteers from different cultural groups to assist with advocacy, support, and interpretation for Newcomers.
 - Have dvd's in different languages about chronic diseases.

5. Low Income/Poverty

A number of Councils felt that low income and poverty was the most significant barrier to the self-management of chronic disease. Individuals that do not have the income or resources to manage a chronic disease face incredible obstacles in being able to follow through on their treatment plan. Managing a chronic disease is expensive. You need to buy nutritious groceries, prescriptions, medical devices, fitness program fees, even a scale to weigh yourself. Poverty effects people's ability to have a proper diet and exercise regime to keep their chronic disease in check and maintain quality of life. Groceries available at food banks often do not include sufficient fruits and vegetables and other nutritious food.

There is a range of poverty - from those who are homeless and more prone to chronic disease, who have no support or transportation to get to appointments, to the working poor who can't always access income supplement/health benefits that are available, to others receiving employment income assistance. Because of the episodic nature of chronic disease, the fact that there are times of wellness and times of extreme illness, people are vulnerable to losing their jobs. Many then experience difficulties with disability coverage and medical insurance claims. Even getting doctors' notes for missing work as a result of their chronic disease can be too expensive and unattainable for many.

In exploring income barriers, Council members felt that the lower the income someone has, the less able they are to find a solution, access programs, get to appointments, access prescriptions, and stay well. Councils identified issues of inconsistent Pharmacare coverage for some prescriptions and medical equipment as creating additional problems for those living on low incomes. Single parents with low incomes have difficulty going to appointments because they can not afford child care.



IDEAS to address:

- The WRHA needs to explore the relationship between income and health in partnership with other government departments and community organizations and develop collaborative solutions.

- WRHA should advocate for drugs that are not currently covered by Pharmacare to be covered so that people do not have to experience great financial costs in order to follow through on their treatment plan.
- Have food stamps for fresh vegetables and fruit for those on social assistance.
- Advocate for increased diet allowance for those with chronic disease for people on Employment Income Assistance. Need to clarify the link between poverty and the inability to buy healthy food.
- Ensure that people know that they can get reduced fees for recreation programs from the City of Winnipeg, YMCA, Reh-fit, Seven Oaks Wellness Centre, etc.

Appendix A

**Top Barriers to Self-Management of Chronic Disease -
Community Health Advisory Councils**

Council	Barrier #1	Barrier #2	Barrier #3	Barrier #4
Downtown/Point Douglas	Income	Lack of primary care provider or lack of relationship with them	Lack of knowledge/ awareness of chronic disease and treatment options, resources	Language and cultural barriers
River East/Transcona	Poor communication between health care provider and patient and family	Attitude - not following thorough on treatment plan	Insufficient time with health care providers to get info, support, referrals to specialists and community resources	
River Heights/Ft Garry	Lack of coordination of information/care for providers and patients	Lack of awareness of and access to health care services and resources	Lack of income and/or employment	Mental health issues
Seven Oaks/Inkster	Lack of support and advocacy	Language and Cultural Barriers	Lack of knowledge/ awareness of chronic disease and treatment options, resources	
St Boniface/St Vital	Lack of knowledge/ awareness of	Language and Cultural Barriers	Lack of Integrated, coordinated,	

Council	Barrier #1	Barrier #2	Barrier #3	Barrier #4
	chronic disease and treatment options, resources		holistic and patient-focused system	
St James/ Assiniboine South	Lack of support, compassion, and advocacy	Mental health issues	Lack of knowledge/ awareness of chronic disease and treatment options, resources	

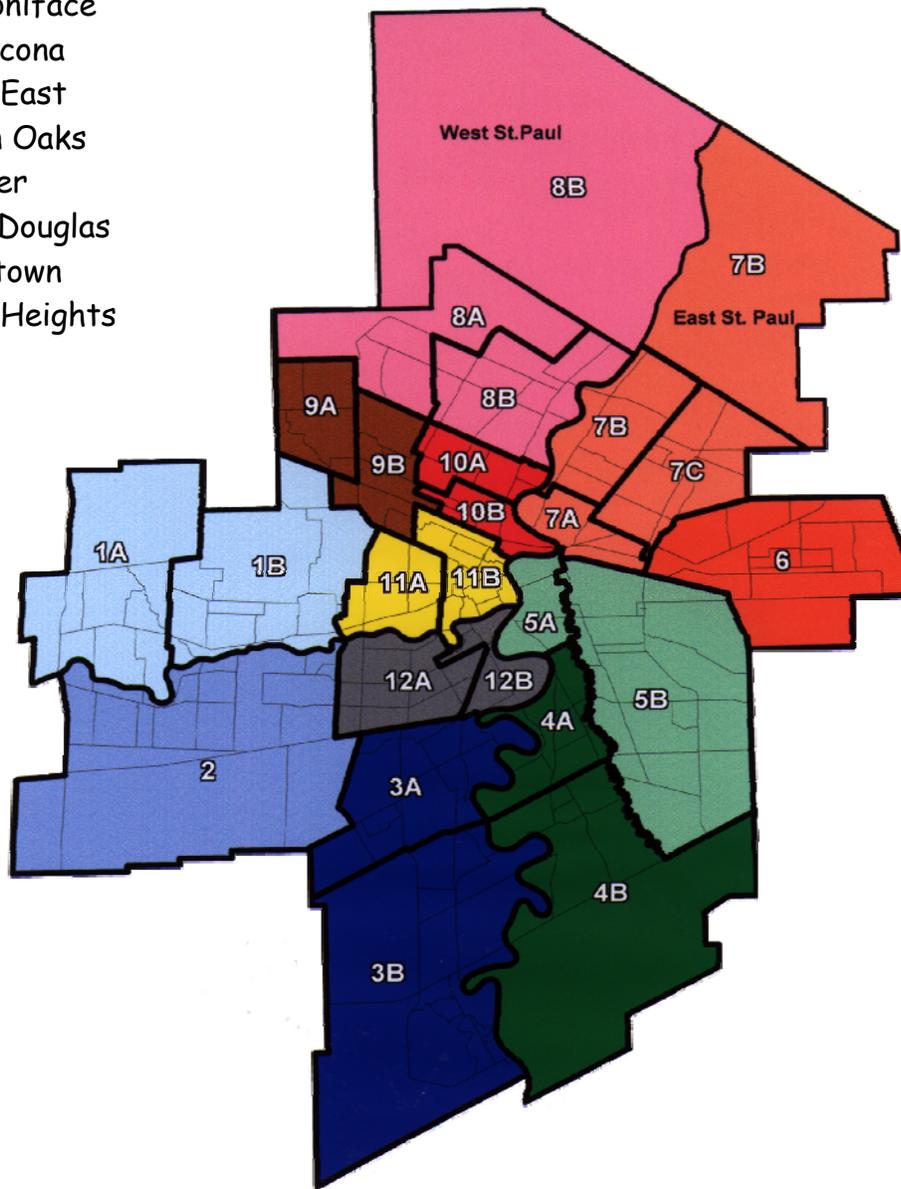
Priority Barriers:

- Number one: Lack of awareness of and access to health care services and resources
- Number two: Lack of primary care provider, good relationship to primary care provider, and lack of integrated approach to care (includes: Poor communication between health care provider and patient and family)
- Number three: Lack of support and advocacy
Mental health issues
- Number four: Language and Cultural Barriers
- Number five: Income

Appendix B

Map of the Community Areas in the Winnipeg Health Region

- 1 St. James - Assiniboia
- 2 Assiniboine South
- 3 Fort Garry
- 4 St. Vital
- 5 St. Boniface
- 6 Transcona
- 7 River East
- 8 Seven Oaks
- 9 Inkster
- 10 Point Douglas
- 11 Downtown
- 12 River Heights



Appendix C

Acknowledgements

Members of the Community Health Advisory Councils

Board Liaisons to the Councils

Support Staff for Councils

Members of Community Health Advisory Councils 2009-2010

Downtown/Point Douglas Council

Elaine Bishop	Richard North
Janice Berens	Janice Shott
Janice Greene	Stephanie Strugar
Jodie Jephcote	Mari Udbarbe
Betty Juselius	Bienvenu Viku
Martin Landy	Barbara Zimrose
Kate Mann	Shannon Zywina
Jan Miller	
Janice Shott	

River East/Transcona Council

Jessica Clark	Eugenia Lehman
Roy Dixon	Joe Lesko
Johanne Drabchuk	Nafisa Pameri
Merle Fletcher	Lora Pickard
Starr Harder	Joanna Poniatowska
Kim Jenkin	Debra Stockwell
Henry Kraft	

River Heights/Fort Garry Council

Nancy Barkwell	Amy Li
Grazia Bermisa	Lydia Loewen
Kuldip Bhatia	Lindsay Mackay
Tara Carnochan	Mathew Maniate
Michael Edwards	Lynn Pierre
Krista Halayko	Betty Schwartz
Mark Holdsworth	Bruce Thompson
Tannis Kircher	Joseph Wall

Seven Oaks/Inkster Council

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Marie Dame
Louise Gowryluk
Gerri Hamilton
Lilah Jackson
Catherine Lee
Dwane Novak

Len Offrowich
Lili Scarrott
Mohindar Singh
Teresa Tacci
Cheryl Woychuk
Alissa Zimmer

St. Boniface/St. Vital Council

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Mian Hameed
Christine Kun
Joanne Legault
Sheri Linstead
Roland Marcoux

Trevor Markesteyn
Gary McPherson
Alioune Ndiaye
Nathaniel Ondiaka
Sory Sacko
Sara Scott
Charlette Treddenick

St. James-Assiniboia/Assiniboine South Council

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Carol Loader
Alison McKay

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Ally Mironiuk
Nancy Nagy
Angela Tessier
Patricia Winton
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Tara Carpenter	River Heights/Fort Garry
Kathleen Clouston	St. Boniface/St. Vital

WRHA Board Liaisons (non-voting members of Councils)

Belinda VandenBroeck	Downtown/Point Douglas
Herta Janzen	River East/Transcona
Vera Derenchuk	River Heights/Fort Garry
Bob Minaker	Seven Oaks/Inkster
Gail Wylie and Louis Druwé	St. Boniface/St. Vital
Kris Frederickson	St. James-Assiniboia/Assiniboine South

Community Area Directors (non-voting members of Councils)

Tammy Mattern	Downtown
Eckhard Goerz	Point Douglas
Debra Vanance	River East/Transcona
Eliette Alec	River Heights/Fort Garry
Carmen Hemmersbach	Seven Oaks/Inkster
Susan Stratford	St. Boniface/St. Vital
Anita Moore	St. James-Assiniboia/Assiniboine South

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