



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”**



## **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.

*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.

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## 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 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.

## Section II

# Reports by Council

## **Downtown and Point Douglas Community Health Advisory Council – First Meeting**

The following notes are from this Council's first meeting on chronic disease, Members provided input on the following questions:

- What is chronic disease?
- 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?

### **What is Chronic Disease?**

- On-going, lasts your life time
- Can change, fluctuate
- Illness that drags for extended periods of time, incurable but manageable
- Progressive
- Not a state of health/well-being
- Impediment
- Some communicable diseases can become chronic conditions
- Could worsen
- Inter-connective
- Restrictive
- Not curable
- Can manage the condition -- stay as healthy as possible and maximize quality of life
- Includes mental health conditions - like bi-polar illness
- Impacts family and people around them
- People can adapt
- Many people end up in long term care
- Constant consumers of health care
- Could be preventable
- Hard to get good diagnosis
- Those with lower incomes are more impacted by chronic disease
- Need full assessment
- Examples of chronic diseases:
  - Bi-polar illness

- COPD - chronic obstructive pulmonary disease
- Diabetes
- Arthritis
- Multiple sclerosis
- Heart disease and stroke
- AIDS
- High blood pressure

### 1. **Improving Access to Primary Care Providers:**

- Some doctors just refer patients with chronic disease to specialists - takes a lot of time before appointment
- Providing care to patients with chronic disease requires good background knowledge that all doctors may not have
- Coordination of care is difficult
- Lack of follow-up after tests and appointments with specialists - would be great if they followed up with patients after a period of time to check in to see how you're doing
  - Should be "shortcuts" to be able to get appointments to specialists that you have already be referred to
- Should be less appointments - this would lessen stress on patients
- Doctors who can diagnose you in one or two visits
- Need to consider how the patient feels
- Access centres would be great places to hold chronic disease clinics
- Need to look at how all systems are involved - those on Employment Income Assistance - to be able to assist patients who are struggling with insurance coverage issues, etc.
- Electronic health records that can be accessed by all health care providers are critical
- Don't make appointments 3 weeks ahead - just call 2-3 days ahead - need a different way of booking appointments - "advanced access"
- Begin with assessment, then build care plan - are they able to manage own care?
- Fee for service doctors - run as business - can only see patients for one issue at a time - because of billing issues - not easy when you have multiple issues living with a chronic disease
  - Protocol - appointments are booked as under 10 minutes or over 10 minutes, with one issue per visit
- It is hard to find a family doctor who can see chronic disease patients

- There are also salaried physicians (work for community health agency, WRHA primary care clinic, etc.) and some who receive a combination of fee for service/incentives and salary - can see patients for multiple issues and for longer periods of time - they aren't as limited as fee for service in how they can provide care
- Continuity of care is really important - it is important that the doctor/ health care provider knows the patient well - it is frustrating to have to retell your story over and over again
- It is important for all health care providers who provide care to a specific patient with chronic disease - have access to their chart - it is also important for the patient to be able to access their chart
- It might be helpful if doctors were paid for over the phone consultations or to share test results - that way patient doesn't always have to go in person for appointments
- Potential to use Health Links/Info Santé to get advice about your condition or to ask questions about worsening condition, etc.
- Difficult to find family doctors - especially for the elderly and those with chronic conditions - their access to the system as a whole (specialists, diagnostic tests, etc.) is compromised
- Walk-in clinics - need to attend clinic 3 separate times in order to get a referral to a specialist

## **2. Chronic Disease Care Team:**

- Team approach is excellent - with coordinator who communicates with the family (often you only see this kind of approach during end of life care when the patient is dying - like at Riverview - it would be better if we had this approach to keep you healthy)
- Team could help address the physical and mental components of a chronic disease - how it effects you emotionally and how you interact with others
- Need a doctor who can diagnose and has a good background on chronic disease
- Good model for this kind of clinic - "the Wish Clinic" at Mount Carmel Community Health Centre
- Like a rehabilitation team
- Diabetes clinics at Mount Carmel
- Use nurses and nurse practitioners
- Easier access to "wound care", etc. for people with diabetes

- Teach people how to manage their condition
- Clinic would provide total care - social worker, spiritual care worker, nutritionist, physical health - cardio/etc fitness specialist, physiotherapist, dentist, hygienist, chiropractor, massage therapist, health educator, links to home care program)
- Can include students in health professions to help deliver care
- Associations for chronic disease like the Manitoba Lung Association have workshops and educational material
- Important to teach, enable, encourage, and support people so that they can manage their chronic disease
- Naive to think that all people can navigate the health system
- Having peer support would be great - someone who successfully manages their own condition - use support groups, etc.
- Someone to follow-up and check-in with you periodically - to provide update on physical and mental status, to enable you
- Use less expensive health care providers than doctors - nurses, social workers, etc.
- Doctors - diagnose, other health care providers provide other health care support and services
- Arthritis clinic - wonderful, taught to manage pain, illness, long waiting time after referral
- Need for more education about good nutrition
- No accessibility to second opinion - people would be able to get second opinion
- Form teams to work with people with chronic disease
- Too much responsibility on doctors shoulders - reduce wait times - by incorporating other professionals in care team

### **3. Considerations for Vulnerable Populations (living with chronic disease) and how they access primary care:**

- Elderly, who may not drive
- Those with mental health issues, dementia, etc. who may or may not be able to manage their own condition
- People with disabilities - diagnostic technology can not always accommodate
- Mobility and access issues
- Need to ensure that equipment and sites are accessible - new buildings should be accessible

- At Cancer Care Manitoba - patients get parking passes - this is helpful
- Consider barriers in transportation and drop-off, Handi Transit - should drop off closer to office/clinic
- Chronic disease visits - doctors' notes for missing work, etc. as a result of their condition - are not affordable for many people
- Child care - single parents may have difficulty going to appointments because they do not have child care
- May not be able to phone to make an appointment
- Worried about stigma - like walker, oxygen
- Lack of resources to run recreational programs that support people
- Lack of money for nutritious foods, lack of knowledge about cooking, etc.
- Community kitchens are very helpful
- Language and cultural barriers - wait time for interpretation services
  - Many people are not used to challenging and questioning authority - which is sometimes useful when advocating for yourself or family member - they just accept what the experts say
- Deaf community
- Outreach workers to help newcomers and take to doctors' appointments - deal with cultural differences and inform them about how care is provided here, etc.
- Have nurses, geriatric care providers, occupational therapists, etc. go out to seniors centres and other community centres to provide care to people there - move more services into the community for those who can not get out - especially in the winter
- Have teams visit house-bound people in their homes
- Lack of accessible housing that is affordable
- There is a good number of people who can not manage their own condition and navigate the health system
  - Need to assess each person's ability to manage and navigate
  - Should extend helping hand - use social workers, etc. to assist with coordination of care

## **Downtown and Point Douglas Community Health Advisory Council – Second Meeting**

The following notes are from this Council's second meeting on chronic disease, Members provided input on the following question:

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

### **Income**

- Child care - single parents may have difficulty going to appointments because they do not have child care
- Chronic disease visits - doctors' notes for missing work, etc. as a result of their condition - are not affordable for many people
- May not be able to phone to make an appointment
- Lack of money for nutritious foods, lack of knowledge about cooking, etc.
- Community kitchens are very helpful
- Can't access transportation to get to appointments, resources, programs, etc.
- No phone
- Lack of resources to run recreational programs that support people
- Food banks - very limited to what they can provide - cheap food, very starchy
- Try to do the things you need to do to live and survive - with very little money - difficult going to many different stores to find well priced vegetables, etc.
- Certain medications that you are prescribed are not covered by Pharmacare - some may/may not be covered by treaty
- Barrier re: food - bylaws/regulations on food handling - re giving away moose meat, etc.

### **Lack of primary care provider or lack of relationship with your primary care provider**

- Lack of primary care physicians - lots of walk-in clinics - no doctor/patient relationship - lack of continuity of care
- Doctors have more work and have all the responsibility - overloaded while the nurses could be doing this work - getting more responsibility
- Insurance/medical leave process - can be barrier - especially if you don't have a doctor you have a long term relationship with - not able to know

patient well enough to vouch for physical and mental health issues that may require medical leave from work

**Awareness of all resources, programs, services, like interpreters, etc. and awareness/knowledge and info on chronic disease, treatment options, etc.**

- Lots of programs, lack of awareness of them
- Native Communications Inc. - really good - could be helpful re sharing info on managing chronic disease, etc.
- Lack of experience, knowledge about planning and cooking nutritious meals, on small budget - community kitchens could be really helpful to address this
- Need information on where to go, consult on nutritious foods, etc.

**Language and Cultural Barriers** (including literacy and other communication barriers)

- Deaf community - face communication barriers
- Illiteracy - embarrassing to ask for help, average reading level of grade 7, many can't read directions, medication, etc.
- Wait time for interpretation services
- Many people are not used to challenging and questioning authority - which is sometimes useful when advocating for yourself or family member - they just accept what the experts say
- Outreach workers to help newcomers and take to doctors' appointments - deal with cultural differences and inform them about how care is provided here, etc.
- St Boniface - not offering all services, no family doctors, French services not offered
- Majority of French families do not go to Centre de Santé
- More Newcomers with different cultures - here, we wait for them to get the information for themselves - we need to go to them, bring the information to them - workshops, in ways they can understand, need to consider some will have decreased literacy level and become lost because they cannot understand
- Newcomer population - language is a very big barrier for them - difficulty with language makes everything else difficult - and health care system is so different from what many are familiar with - like how long you must wait to see a doctor

- Not able to communicate, you're ill, relationship with health care worker is not there, no continuity
- Relationship with health care provider is entirely different - this is a cultural issue
- Need interpreters to be more available, accompany to appointments, help express feelings
- Health services in French language - obligated to offer primary care services in French - through Centre de Santé and Info Santé
- Aboriginal people may experience language barriers as well

#### **Difficulty in navigating the health system and advocating for themselves**

- Unable to navigate the health system
- There is a good number of people who can not manage their own condition and navigate the health system
- Need to assess each person's ability to manage and navigate
- Should extend helping hand - use social workers, etc. to assist with coordination of care
- Patient advocate from MB Métis Federation to assist people with cancer - helped with all aspects of chronic disease management

#### **Lack of linkages between modern/western medicine and traditional/alternative medicine**

- Traditional medicine versus modern medicine and other alternatives - need good advice from qualified alternative medicine leaders like elders and others
- Alternative medicine not covered by insurance, etc. for most people
- Need direction with herbal treatments, especially when you're taking other medication
- Health care providers not being sensitive to alternative medical treatments that people with chronic disease may be interested in pursuing
- Western medicine is not the be all and end all

#### **Mobility barriers, disabilities, elderly**

- Age and mobility and physical disabilities
- Elderly, who may not drive
- People with disabilities - diagnostic technology can not always accommodate

- Mobility and access issues
- Need to ensure that equipment and sites are accessible - new buildings should be accessible
- Have teams visit house-bound people in their homes
- Consider barriers in transportation and drop-off, Handi Transit - should drop off closer to office/clinic
- At Cancer Care Manitoba - patients get parking passes - this is helpful
- Have nurses, geriatric care providers, occupational therapists, etc. go out to seniors centres and other community centres to provide care to people there - move more services into the community for those who can not get out - especially in the winter
- Lack of accessible housing that is affordable

#### **Lack of motivation**

- Worried about stigma - like walker, oxygen
- Lack of motivation --- come up against all of these barriers and kind of give-up - it takes a lot of work/effort to manage a chronic disease
- Managing diet - some people just don't - they see others able to eat everything and find it very hard to stay focused, motivated

#### **Mental health issues**

- Those with mental health issues, dementia, etc. who may or may not be able to manage their own condition
- Clients with mental health issues - walk-in clinics - need three appointments before you can get referral to psychiatrists

### Prioritization of Barriers to Self-management of Chronic Disease:

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.

### Barriers ranked:

1. Income (12 points)
1. Lack of primary care provider or lack of relationship with your primary care provider (12 points)
2. Awareness of all resources, programs, services, like interpreters, etc. and awareness/knowledge and info on chronic disease, treatment options, etc. (9 points)
3. Language and Cultural Barriers (including literacy) (8 points)
4. Difficulty in navigating the health system and advocating for themselves (5 points)
4. Lack of linkages between modern/western medicine and traditional/alternative medicine (5 points)
5. Mobility barriers, disabilities, elderly (4 points)
6. Lack of motivation (3 points)
7. Mental health issues (2 points)

### **1. Income (12 points)**

- The council discussed the challenges related to trying to come up with suggestions for how the WRHA could address this barrier
- Council requested that the report reflect how important they felt income was in how people were able to manage their chronic disease
- Only suggestion for the WRHA was to address the relationship between income and health in partnership with other government departments and community organizations
- Council decided to focus their efforts on the next top 3 barriers - see below

- 1. Lack of primary care provider or lack of relationship with your primary care provider (12 points)**
  - Need for more doctors, nurse practitioners, etc. - look for alternative health care providers who can spend more time developing relationship with patients as part of the health care team
  - Look at numbers of doctors in North End - too many walk in clinics
  - Deal with the issue of doctors not taking new patients with chronic disease
  - Hold a public information campaign about importance of having a good and supportive relationship with your doctor
  - Educate doctors and other health care providers about the importance of developing relationships with their patients
  - More education about chronic disease for public so they go to doctors appointments with more knowledge
  - Need to make people aware of what patients can do for themselves - know what you need to know about your body/health/self
  
- 2. Awareness of all resources, programs, services, like interpreters, etc. and awareness/knowledge and info on chronic disease, treatment options, etc. (9 points)**
  - Bring speakers into community organizations to talk about their chronic disease association, what they do, etc.
  - Bring chronic disease support groups - like Lung Association, Cancer Society, etc. to speak at community groups
  - Community agencies are the best advocates for people in their community
  - Have staff at community health clinics that can refer people with chronic disease to programs and treatment options, services, etc.
  - Get information out to people about alternative health programs - like traditional Aboriginal medicine
  - Health Links/Info Santé - promote this more - have them provide information to people with chronic disease about services related to their chronic disease
  - Have chronic disease resources bookmarked on the WRHA website
  - Put information on chronic disease resources and groups in the telephone book WRHA insert
  
- 3. Language and Cultural Barriers (including literacy) (8 points)**
  - Community is becoming more diverse - Newcomers, Aboriginal, etc.

- Thin line between recognizing cultural differences and segregating cultures
- Health care workers need to be aware of differences between cultures
- Develop health advocates to assist Newcomers
- Important to consider "how" we give information - and learn how different cultures would prefer to receive information - develop strategies based on this
- Welcome Place and International Centre - could partner with them to develop health advocacy strategies, assistance with acclimatization, interpreters, etc.
- Need to consider lower levels of literacy and basic understanding
- Mentoring of newly arrived Newcomers with those who have been here much longer
- Being aware of cultural taboos - like not speaking about sexuality in front of children
- Tele-health interpreters - for remote communities - not everyone will have an interpreter
- Support for primary care physicians with interpreter services/phone line, etc.
- Importance of awareness of cultural rituals associated with different aspects of health care - like ob/gyn, etc. - need to ask people what is important to them, as part of their culture related to whatever health services they are receiving

## **River East and Transcona Community Health Advisory Council – First Meeting**

The following notes are from this Council's first meeting on chronic disease, Members provided input on the following questions:

- What is chronic disease? (did not take notes on this question at this Council's meeting)
- 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?

### **1. Improving Access to Primary Care Providers:**

- Visible clinics in the community are helpful - getting care from access centres
- Wait times to see specialists are too long
- There are challenges of limited physical space and time for appointments
- Start at "frontline" - receptionists - to be aware of "chronic diseases" and to prioritize those patients with chronic disease to get appointments sooner - phone triage at clinics
- Right now, if you have a crisis with your chronic disease - often get referred to emergency department - and you end up waiting there for 10 hours - you shouldn't even bother
- Stages in illness where you're looking for cure, then next step, when it's chronic - what do you do to live with it? Manage it?
  - Managing at "medical front" with additional community resources like Canadian National Institute for the Blind, Canadian Diabetes
- Referral to special clinics when you're discharged from hospital
- Importance of the individual understanding their chronic disease condition - need the right amount of education over a period of time - it will be the responsibility of the patient to say "I don't understand", but patients are afraid to admit that
- Doctors and health educators need to explain things simply
- Need to consider that it will be difficult for people who get really ill to access their regular care

- Schedule home appointments, visits - care givers will gain more insight into the patient and some of their challenges, etc.
- The need for long term, continued contact - to keep people healthy, not just reacting when their condition worsens
- Have the right provider address the appropriate aspect of their condition - need for support and counselling
- Need to consider that over time, people with chronic disease will feel like they've heard it all before
- Home visits to diabetic patients in Jamaica program - care providers check patients' medical supplies, take blood pressure, check feet, clip nails, talk about nutrition, etc. - community nurses do outreach into the community, will refer people to clinics, if their condition worsens, or if they are in need of specialists - they get referred to the hospital
- Mobile clinics to communities - take nurses into the community, use peers, volunteers to assist
- Use Health Links/Info Santé
- Cultural community centres - arrange for blood pressure check up at seniors centres, etc, get information on other resources, access centres, etc.
- Have companies run their own clinics - be trained to do a variety of tests, etc. at the work site
- Connect with settlement workers, International Centre, etc. to provide care for Newcomers --- have special clinics for Newcomers
- Don't always need to see a doctor
- Other non-profits that are already going into peoples' homes and provide other services to people with chronic disease
- Keeping a number of appointments open every day at clinics - for urgent care, triaged over the phone, could be seen by nurse at emergency
- Schedule of appointments for patients with particular 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

## **2. Chronic Disease Care Team:**

- Homeopathic care
- Aboriginal care providers
- Chiropractors

- Roles from nurses - may have received training from country of origin - may not be licensed here - from different countries, cultures - can provide support and counselling
- "chronic care" clinics - like Youville Centre - if clinic specializes, then move regular patients elsewhere
- Nurse practitioners could run clinics, have specialists as consultants, don't have to be physically there, like endocrinologists for diabetes
- Occupational therapist
- Newcomers who are former doctors and nurses - could play critical role as part of health care team, help with home visits, etc.
- Physiotherapist
- Social workers - counselling after critical experiences, traumatic, near death - to normalize what you're experiencing - to deal with depression and anxiety, to help family deal with it too
- Educational piece to help people manage their care
- Urgent care
- Home visits - go to the patient in their home - helps care providers understand the context of the patient's situation better, teach self-care, will get better sense of barriers to self-management
- There are those unable to physically get to the doctor's office, etc.

### **3. Considerations for Vulnerable Populations (living with chronic disease) and how they access primary care:**

- Seniors - family members can help keep track of appointments, what was said during an appointment, etc.
- What about people without supports, family, friends?
  - Could a community volunteer help them? (Parent councils, churches, community clubs)
- Newcomers who are former doctors and nurses - could play critical role as part of health care team, help with home visits, etc.
- Newcomers
- Home visits - go to the patient in their home - helps care providers understand the context of the patient's situation better, teach self-care, will get better sense of barriers to self-management
- There are those unable to physically get to the doctor's office, etc.
- Use schools as a vehicle for getting information out to homes - like information on access centres, how the health system works, and other resources in the community, etc.

- Newcomers should be referred to settlement workers to help connect families to health care, resources, information on chronic disease, etc.
- Provide materials in a variety of languages - on chronic disease
- Keep information simple - in clear, simple language
- Keep in mind various cultures in Elmwood - large population from Bosnia - cultural dynamics to be aware of - view of doctor as the be all and end all - need to educate Newcomers about the role of nurse
- Use schools to inform students - share information with families

## **River East and Transcona Community Health Advisory Council - Second Meeting**

The following notes are from this Council's second meeting on chronic disease, Members provided input on the following question:

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

**Attitude** - denial, not following through on treatment/self-management plan

- Attitude - denial until their condition worsens - may have family members/friends that don't believe they have a chronic illness - "making it up for attention"
- Lack of willingness of person to follow through on medication and other aspects of self-management of their chronic disease
- Why are they not following through? That's the question that needs to be asked

**Income** - can't access resources, nutritious food, medicine/prescriptions, medical devices

- Not having income, resources to manage a chronic disease - to pay for prescriptions, diabetes testing kits, medical devices, nutritious food, etc. - even a scale to weigh yourself
- Budget, income, financial limitations
- Expense of nutritious foods in northern communities

**Poor communication between health care provider and patient** - lack of trust, empathy, understanding of patient's barriers, and attitude of "caring for them" instead of "supporting them"

- Individuals own ability to understand/comprehend what they have been told - re: self-management - nutrition, for example
- Communication barrier between health care provider and patient - may be afraid to ask questions when they don't understand - role health care provider to provide information on a level that the patient can understand
- Service providers - can be barriers themselves - "I'm going to care for you" versus "I'm going to support you" - providers should be identifying the barriers and help people develop strategies to address them - people are capable of caring for themselves

- Education aspect - seriousness of it needs to be explained but provide direction for what people can do - shouldn't just lay down and die - needs to be explained/broken down so it is understandable and then they can cope
- Communication/understanding - promoting a positive lifestyle is important
- Lack of trust between health care provider and patient
- Lack of observation skills and communication skills - health care provider
- Lack of truthfulness of patient - for example, patient states that they are doing everything they've been told to do - like removing old rugs, cat, not smoking, etc. - but they have not - and end up in emergency department again
- Lack of empathetic ear from health care provider
- Making the assumption that everyone has the same quality of life in their home environment
  - Need to ask/be more assertive of what barriers people are facing in their home life
- Lack of follow-up, continuity and consistency of care
- Should be focusing on preventing chronic disease - encouraging traditional ways of life, food, etc.

**Lack of awareness of reliable information on their chronic disease, treatment options, and resources in the community**

- Knowledge of programs, professionals, etc. to access for their chronic disease
- Difficulty in determining what alternative medical approaches could be helpful - self-prescribing other remedies, like herbal and "Dr Google" - using the internet to find out more information but not knowing if the sites are legitimate/accurate, etc.
- It needs to be up to the person to decide, also need to trust healthcare provider re: information on chronic disease, etc.
- Lack of understanding by the greater public/society about what chronic disease is and how serious it is

### **Language and cultural barriers**

- Newcomers - language barriers, ability to understand (may say that they understand when they don't), need support, assistance to understand
- Brochures are in English and French only
- Afghan community - leader has pretty poor English - can be a barrier to liaising with health community
- North American approach to educating may not work with other cultures
  - Would need to be taught in own cultural style
  - Not taking nurses seriously, only listening to/trusting doctor
  - Not questioning doctors
- Traditional Aboriginal communities - may need different teaching style - standard approach may not work re: changing behaviours, etc.

### **Difficulty/reduced mobility** - to get to appointments, programs, etc. and in-availability of home-based services

- Mobility - unable to access resources - to physically get out, can't access home care
- Environment - need to make it safe for the person with a chronic disease - smoke, different chemicals, allergies, etc. - need to explain to patient and family what they should avoid in their home environment
- Home visits are important for people with chronic disease - health care provider can check on home environment and life style behaviours, etc. to see if the patient is following through on self-management plan and identify barriers and help them address

### **Lack of support to manage their chronic disease**

- People that don't have support/activities
- Lack of peer support groups
- Need for reinforcement of messages about how to self-manage your chronic disease
- Specific issues for children and adolescents with chronic disease - they need to hear from health care provider about what changes need to happen at home, changes in behaviour, etc.
  - Parents then need to reinforce/enforce this at home
  - Education in classrooms about chronic diseases that kids have

**Insufficient time with health care providers to get information, support, referrals to specialists, community resources, etc.**

- Lack of access to professionals - their caseloads are so large - only have 5 minutes to communicate everything to their patient about their chronic disease - lack of sufficient time with health care professionals - this is where nurse practitioners could come in
- Patients should ask for more time, information, and referrals from doctor - so that they can access more resources, gain more knowledge about their condition, treatment options, self-management, etc.
- Lack of time with health care provider
- The over-professionalization of health care

Prioritization of Barriers to Self-management of Chronic Disease -- addressing the most significant barriers to self-management of chronic disease):

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.

Barriers ranked:

1. Poor communication between health care provider and patient - lack of trust, empathy, understanding of patient's barriers, and attitude of "caring " instead of "supporting" them (23 points)
2. Attitude - denial, not following through on treatment/self-management plan (11 points)
3. Insufficient time with health care providers to get information, support, referrals to specialists, community resources, etc. (11 points)
4. Lack of awareness of reliable information on their chronic disease, treatment options, and resources in the community (5 points)
5. Language and cultural barriers (2 points)
6. Difficulty/reduced mobility - to get to appointments, programs, etc. and in-availability of home-based services (2 points)

7. Lack of support to manage their chronic disease (1 point)
8. Income - can't access resources, nutritious food, medicine/prescriptions, medical devices (no points)

**Top Three Barriers:**

1. Poor communication between health care provider and patient - lack of trust, empathy, understanding of patient's barriers, and attitude of "caring " instead of "supporting" them (23 points)
2. Attitude - denial, not following through on treatment/self-management plan (11 points)
3. Insufficient time with health care providers to get information, support, referrals to specialists, community resources, etc. (11 points)

## Ideas for Addressing Top three Barriers to Self-management of Chronic Disease:

### **1. Poor communication between health care provider and patient - lack of trust, empathy, understanding of patient's barriers, and attitude of "caring " instead of "supporting" them - talking down to patients/poor relationships**

- 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 health care professionals about using plain, simple language, listening skills, etc.
- Address cultural biases within the system - need to be aware of cultural diversity and different ways that people from different cultures communicate
- 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.
- Emphasize the many positives of managing chronic disease
- Educate professionals about the barriers that patients may face/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
- The relationship piece of health care provider and patient is often missing
- Approach needs to be supporting patient not caring for them, person to person as equals, not talking down to them, being more approachable, being a better listener

### **2. Attitude - denial, not following through on treatment/self-management 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
  - Will help them more in defining what their self-management will be

- Shouldn't focus on "illness" instead they should focus on how to be well
- Acknowledge that learning that you have a chronic disease is a loss, but you can still have a good life, manage your illness - it can be the death of a dream - 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
- 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
- Provide home visits to people not accepting their chronic disease or following through - outreach counselling
- Have information for youth at schools to be aware of symptoms of chronic disease and to try and catch them before they develop a chronic disease
- Provide counselling support - would be a benefit to many - social workers, psychologists, etc.
- People need to be ready for behaviour change - family are key to this and others to support is critical

### **3. Insufficient time with health care providers to get information, support, referrals to specialists, community resources, etc.**

- Physicians should refer patient to specialists, programs, etc. that will have the time to speak with the patient
- Encourage patients to bring a list of questions and what they want to accomplish during their next appointment
- Physicians need to spend time with patients to build trust, a relationship
- Need to address the issue of quality versus quantity
- Have other health professionals assist physicians in their offices to provide services to patients with chronic disease - nurse practitioners, etc.
- Have clinics with doctors, nurse practitioners, etc. where patients with a chronic disease can go - can stay on top of symptoms and any changes in physical and mental well-being
- Have community nurses follow-up with chronic disease patients to see how they are doing

- 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.
  - Physicians need to be able to show that their patients are having good outcomes
  - Performance based fee for service outcomes
- Specialists and family doctors should have additional staff to spend time - counselling, educating patients - like counsellors and health educators

## **River Heights and Fort Garry Community Health Advisory Council – First Meeting**

The following notes are from this Council's first meeting on chronic disease, Members provided input on the following questions:

- What is chronic disease?
- 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?

### **What is Chronic Disease?**

- Long term, slow progressing disease
- Condition that requires on-going care
- Relapse and remission - periods of wellness, periods of serious illness/acute symptoms
- No cure, but treatment available
- Maybe associated with some abnormalities - like joint problems, arthritis
- Aggravating, infuriating
- Mental health implications -depression, feelings of hopelessness, anger, anxiety
- Affects ability to have normal, healthy lifestyle
- Lots of doctors appointments, treatment, medication
- Huge implications for family
- Financial implications - especially when medication is not covered by Pharmacare
- Potential stigma
- Treatment requires large team of professionals
- People can seem to be typically healthy
- Decreasing quality of life
- Some look for exceptional cures, treatment out of desperation
- If you can live with a degree of hope, then you can live with it, adapt, it's incurable, there's a finality to it.
- Visits to emergency department

- Examples of chronic disease:
  - Could be physical condition or mental health condition - like post traumatic stress disorder, schizophrenia
    - Auto-immune disorder
    - Multiple Sclerosis
    - Arthritis
    - Asthma
    - Children - ADHD, autism - can continue on to adulthood - sometimes without diagnosis
    - Cancer
    - Parkinson's Disease
    - Macular degeneration
    - Lupus
    - Diabetes

#### **1. Improving Access to Primary Care Providers:**

- Educating health care providers about chronic disease is very important
- Can be difficult to get test results from hospitals
- Many different appointments, providers - can be confusing and difficult
- Need information on where to go for tests, etc. - a coordinated approach would be better
- Education about specific chronic diseases - depends on disease, depends on doctors - there is more information readily available on some chronic diseases, and there are some doctors who share this information more readily than others - needs to be a consistent approach to sharing information with patients
- Patient need to be able to manage own care - also doctor's responsibility - many people won't understand
- Diagnosis of chronic disease - sometimes disagreement
- Doctors can lose track of patient - sent all over the place, may have mobility issues, financial stress of transportation and parking costs associated with all of the appointments
- Family members under huge stress to take member with chronic disease to appointments, etc. - some have to quit their jobs
- Lots of pressure on family doctor - they send you off to other specialists
- Family doctors need to know their patients
- Family doctors have lots of patients, and it takes a lot of time to manage patients with chronic disease

- Issues of how family doctors are financially compensated for appointments - treating chronic disease patients takes a lot of time, might not be conducive to how they want to run their practice - "One issue per visit" - this won't work if you have a chronic disease and have multiple health issues that need to be addressed at doctor's appointment
- Looking for family doctor? Doctors don't want new patients with chronic disease
- No incentives for doctors to take on patients with chronic disease
- Phenomenal amount of pressures out there - lack of coordination - need for seamless approach to this

**1. Detection/Prevention**

**2. Diagnosis**

**3. Treatment**

**4. Follow-through** - continuing education, how you live with it, how you adapt, change your lifestyle, etc.

Have teams that work across and coordinate

- Example of British system where doctors get paid more for improving health of patients
- On-going management/treatment - don't necessarily need specialists involved all of the time
- Over the phone consultation with clinical specialist/nurse practitioners, etc.
- Referral process can cause bottlenecks see specialist, never get back to family doctor
- Chronic disease clients get neglected, acute care patients have attention of healthcare system
- Walk-in clinics - family doctors "feels like a superstore" (in and out)
- Different levels of familiarity with different chronic diseases - might only have one patient with Lupus - so that doctor would need to refer the patient to a specialist

## 2. Chronic Disease Care Team:

- Case manager - so important - "holding the reins" going in the same direction, good communicator, coordinator, recommendations of different team members, enable process
- Lots of health care workers who could be trained to keep costs low
- There is a great team for children and adolescents with diabetes - this is a great model - one place, access all professionals - could be done for different types of diseases
  - Endocrinologist, doctors, dieticians, social worker, nurse
  - You see everyone, every time you visit the clinic
  - Fantastic
  - But, when you turn 18, this approach ends - you have your doctor, but no-one else - multiple appointments in different locations
- Need for coordinated approach to chronic disease care - in one place
- Family members - perhaps there is more that can be done by family at home, take pressure off the health care system
- Patient should be responsible for managing their chronic disease if they are able to
- Potential roles for volunteers to support, advocate for person with chronic disease, assist with appointments, etc.
- Teams of clinicians working together - consult with each other
- "Shared care" model - counsellor linked to family doctor practices to assist with mental health issues of patients - they have time to give to patients - this could be a good model to use to support family doctors in providing care to their patients with chronic disease
- Can't necessarily have clinic teams for every chronic disease - but case manager approach could help coordinate treatment
- Nurse practitioners - take load off family doctors - can be trained in specialties
- Cancer Care Manitoba - is a good example of different specialists being brought together - couldn't we have this for other chronic diseases?
- Pan Am Clinic - specialty clinic - good team, approach to care
- Nurse practitioners in family practices - role to manage care for patients with chronic disease
- Use clinical assistants
- Potential role of Health Links/Info Santé - have phone access to care 24 hours a day/7 days a week

- Have an after hours- physician on-call - to triage over phone to specialist - goal to keep people out of ER's after hours, when family physicians are not available
  - Monitoring calls to help manage self-care
- Use technology to provide information and address treatment issues
  - Packages sent out via email
  - Internet chat about different chronic diseases
  - Use skype to provide care
  - Professionals could serve 100's of patients using technology
  - On-line question and answer - like "Virtual Hospice" approach
- Issue of family doctors working as hospitalists - taking doctors out of community practice and primary care where they are needed
- Patient support groups - peers together, supporting one another, self help approach - could have doctor to support group

### **3. Considerations for Vulnerable Populations:**

- Shouldn't assume that everyone has computer and internet access, skills
- People who speak other languages - need to address language barriers in order for everyone to be able to access care and information about chronic disease
- Need to consider isolated, Northern communities - people come into Winnipeg to receive care
- Need to consider how difficult it is for low-income single parents to be able to manage - financial issues, time for appointments, etc.
- Need to consider people who don't have financial resources, their own transportation
- Need to consider how homeless people access primary care - how to assist
- Need to consider that most people are not aware of the health services that exist
- Need to consider mobility challenges for many with chronic disease - difficult for them to get out of the house, get to appointments - what about taking care to peoples' homes? Doctors who make house calls, over the phone consultation - could that meet some of the needs?
- Need to consider people with behaviours that create issues with their health care provider - they become angry, depressed
- Need to consider people with mental health issues - many have difficulty accessing care

## **River Heights and Fort Garry Community Health Advisory Council – Second Meeting**

The following notes are from this Council's second meeting on chronic disease, Members provided input on the following question:

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

**Lack of access to and awareness of health care services, health promotion resources, etc.** (includes decreased mobility, lack of transportation, long waits, services not in community)

- Lack of safety, fear of leaving their home to go to appointments or to access community resources for their chronic disease
- Lack of transportation – being able to get to appointments, inconvenience of parking, cost of transportation and parking
- Lack of awareness of services, resources, and treatment options in own community
- Too much information – like what is on the internet
- Too many rules, etc. using Handi Transit
- Family doctor is unavailable or inaccessible – can't phone with a question
- If you live in a rural area, it is difficult to get to services that don't often exist in your community
- Health condition itself can be a barrier – like Alzheimer's
- Difficulties with transportation and lack of support to get to doctors' appointments and programs
- Disabilities associated with some chronic diseases – vision impairment, etc.
- Seniors – may not have family support that would help them get to appointments, etc.
- Mobility – physical ability to get out – accessing care and getting physically active

**Lack of coordination of information/care for providers and patients** (needing to access family doctor to get access to other specialists, etc., fragmentation of services, etc.)

- Lack of coordinated care, consistent message from health care providers – different and conflicting approaches suggested by different care providers makes it very confusing

- Lack of central point/clearinghouse of information on treatment options and services for chronic disease
- Having to wait to see a doctor - if you have a question about self-care - referrals to specialists can take a long time, condition can worsen
- Fragmentation of services - one place to see social worker, one place to see doctors, etc.
- Lots of information but coming from many different sources
- Lack of access to diagnostics, etc. by doctors, specialists - having to repeat tests
- Not having a family physician - need to access the rest of health care system and the chronic disease itself can be a barrier to getting a doctor
- Patient requires care and support from other specialists (like occupational therapists) but care isn't integrated, so they don't receive it

**Mental health issues** like depression, lack of motivation, feeling isolated, not connected to others with same chronic disease, episodic nature of chronic disease

- Challenges of motivation and sticking to the care plan - changing patterns of behaviour is very difficult
- Isolation - aren't enough programs to provide emotional support
- Episodic nature of many chronic diseases make it difficult to stick to treatment program - sometimes you are very ill and you focus on self-management, other times when you're not very ill, you lose focus or stray from self-management plan
- Need to talk to others about their chronic disease - peer support groups - especially for rare chronic diseases
- Lack of motivation - intense recovery - can be short term and then they lose motivation and their condition worsens
- Depression - as progress worsens, people become more depressed, have no motivation to follow treatment plan
- Mental health issues can be a barrier
- Loss of memory - makes it difficult to take medication, remember doctors' appointments, etc.

**Lack of income/employment** - cannot afford medication and health promotion activities, no access to nutritious food, problems with disability insurance/pensions, times of wellness and illness when you cannot work

- Lack of income - unable to afford medication, health promotion activities

- Poverty, living on the streets, homeless and more prone to chronic disease, have no support, transportation, etc.
- Working poor - can't always access programs like people on Employment Income Assistance, etc.
- Poverty - affects ability to have proper diet/nutrition and decreases their ability to be able to stick to their treatment plan

**Having multiple chronic diseases** - multiplies barriers experienced

- Some people have multiple chronic diseases which creates a very complex health situation for them and multiplies the barriers that they face to managing their condition - difficult to prioritize self-management

**Communication barriers** - language, literacy, being afraid to ask question when you don't understand, disabilities

- Lack of cultural awareness of different ways cultural groups may perceive chronic disease - some people may be afraid to ask for help because within their culture the response may be "just pull up your bootstraps" or "just grin and bear it"
- Language barriers - different languages and literacy levels - make it difficult for people who don't speak English or French to communicate with health care provider and read materials about their chronic disease
- Literacy issues - doctors explain condition and treatment with complex terms, patient might say that they understand but they might not, afraid to ask questions or ask for it to be explained more simply - also not enough time to ask questions

**Stigma of chronic disease** - includes ageism

- Stigma associated with some chronic diseases like mental health conditions - hard to accept, to tell others - challenging, some people hide from the truth of it and therefore don't get any support which can lead to other problems
- Ageism - perception that the person is just "aging" - health providers not taking their chronic disease symptoms, condition seriously
- Age - harder for young children to ask for help

Prioritization of Barriers to Self-management of Chronic Disease --  
addressing the most significant barriers to self-management of chronic disease):

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.

Barriers ranked:

1. Lack of coordination of information/care for providers and patients (needing to access family doctor to get access to other specialists, etc., fragmentation of services, etc.) (22 points)
2. Lack of access to and awareness of health care services, health promotion resources, etc. (includes decreased mobility, lack of transportation, long waits, services not in community) (13 points)
3. Lack of income/employment - cannot afford medication and health promotion activities, no access to nutritious food, problems with disability insurance/pensions, times of wellness and illness when you cannot work (12 points)
4. Mental health issues like depression, lack of motivation, feeling isolated, not connected to others with same chronic disease, episodic nature of chronic disease (10 points)
5. Communication barriers - language, literacy, being afraid to ask question when you don't understand, disabilities (3 points)
6. Stigma of chronic disease - includes ageism (no points)
7. Having multiple chronic diseases - multiplies barriers experienced (no points)

Top Three Barriers: (group decided to provide suggestions for top 4)

1. Lack of coordination of information/care for providers and patients
2. Lack of access to and awareness of health care services, health promotion resources, etc.

3. Lack of income/employment
4. Mental health issues like depression, lack of motivation, feeling isolated

Ideas for Addressing Top four Barriers to Self-management of Chronic Disease:

- 1. Lack of coordination of information/care for providers and patients**
  - Health care should be more client focused
  - Should be a team approach to providing health services to people with chronic disease
  - Should be one point of contact/clearinghouse for information about chronic disease and where people can ask questions, etc.
  - Need central information point - on-line - that lists all resources for people with chronic disease, support groups, who to contact
  - Create advocate positions to assist those without any support who need assistance/support in navigating the system and having their needs met
  - Use model from other clinics - like diabetes clinics - providing access to a team of health care professionals
  - 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
  - Consider the use of others like nurse practitioners
  - Needs to be a feedback, proactive feedback system to patient with their involvement
  
- 2. Lack of access to and awareness of health care services, health promotion resources, etc.**
  - Provide assistance with transportation to those who need it - partner with charities, volunteer driver programs, United Way
  - Provide care in peoples' homes who can't leave their homes, who are not mobile
  - Improve accessibility to primary care where more of a patient's health needs can be met - physical, mental, and emotional

- Improve access to family physicians - address those people who don't have a family doctor
- Make changes in the fee for service policies - like one issue per visit - so that patients can spend more time with their family doctor
- Encourage a change in the way physicians practice
- Consider the use of physician assistants

### **3. Lack of income/employment**

- 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 - 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.

### **4. Mental health issues like depression, lack of motivation, feeling isolated**

- Create peer support groups for chronic diseases
- Need to address the intimidation that some people may experience like when attending a gym or attending cardiac rehab for the first time
- The system needs to reach out and support patients

## **Seven Oaks and Inkster Community Health Advisory Council – First Meeting**

The following notes are from this Council's first meeting on chronic disease, Members provided input on the following questions:

- What is chronic disease?
- 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?

### **What is Chronic Disease?**

- Not curable, not acute
- Manage to prevent further deterioration
- May be physical, mental, emotional
- May be life style related
- On-going - some may outgrow - for example, asthma
- May not get better but some are manageable
- Some disorders can be corrected through surgery - for example, cardiac disease, cardio obstructive pulmonary disease (COPD), osteoarthritis, asthma, emphysema, cancer, diabetes
- Untreated conditions can be chronic - very important
- Progressive nature and long term
- Psychosocial issues can be chronic
- Persists over time

### **1. Improving Access to Primary Care Providers:**

- Have "pods" co-occurring chronic diseases - where treatment for multiple chronic diseases could be accessed - coordination of treatment/ seamlessness - like geriatric conditions -- physical and mental chronic diseases
- Night care - physicians - travelling, home visits, house-calls
- Comprehensive, diagnostic procedure - longer histories taken - physical, mental, psychological, etc. behavioural
- Finding doctor is difficult, often little relationship between doctor and patient - analyze for one problem - when you have chronic disease - this won't be sufficient/appropriate

- Clinics for chronic diseases
- Electronic health record - comprehensive record of medical history - so your medical history follows you as you go from one appointment to another - one doctor to another, etc.
- Multiple appointments, longer appointments scheduled for patients with chronic disease
- What to do when doctors retire? What happens to patients with chronic disease?
- Need assistance with transportation to appointments
- Mandate of chronic disease associations - they do fundraising for research, have local chapters, national organizations, some services - education, pamphlets, etc.
- Big gaps in service for people living with chronic disease, also potential for duplication of services
- Important to have ability to be seen very quickly, diagnosed, and treatment plans be put in place - use example of Mayo Clinic experience - not piecemeal approach - compression under short time span - specialists, multiple appointments - under one roof
  - We have clinics - but don't offer this
- Some chronic diseases - not well known, doctors have little information like epilepsy - can't find others with the same condition, would like to develop support group
- Services, groups, support, etc. - need night, weekend options - everything now seems to be scheduled or happens during the day
- Look at Alcoholics Anonymous model - various meeting times, locations, phone-lines, on-line, etc.
- On-line question and answer web pages for different chronic diseases
- People living with chronic diseases are most stressed at night - there should be some way to contact primary care/get feedback from a physician, other than visiting emergency department
  - Health Links/Info Santé - helps alleviate stress, anxiety at night
  - Need more information about their chronic disease - information on what they can, can't eat, etc. - what are the physical and mental aspects of the disease? - at the point of diagnosis - should get the information about their condition from nurse practitioner, etc.
- Have different appointments for people with chronic disease versus other patients - because they have multiple issues
- Specialists - book multiple appointments for the same time slot

- The emphasis needs to be on health promotion - integrate into whatever we're doing
- When people with chronic disease show-up at emergency, not necessarily the right place, people will have difficulty getting issues addressed

## 2. Chronic Disease Care Team:

- Nutritionists,
- Schools can assist in identifying chronic disease in children
- Social/psychological workers to assess patient's mental well-being, do thorough histories, etc.
- Health educators - to tell people about their chronic disease condition, what to expect, etc.
- Better utilize chronic disease associations like Canadian Diabetes Association - -what is their mandate? - need to connect with these organizations
- Both the family of the patient and other care givers experience a lot of stress - need support too - maybe groups for caregivers
- Clinics should provide follow-up to patients - check in
- Specialized doctors and nurses
- Health coach/supporter
- Self-help, group setting - like "AA" - meetings 3 to 4 times per day, meetings all the time, all over the city
- Self-help groups are offered at Youville Centre - but need a support network - supported by primary care health providers - Nor'West/Seven Oaks initiative
- Role of family - provide support - need to be a part of the process/ treatment, need to learn about chronic disease condition, etc. - should be included in the meetings/appointments with care providers wherever possible
- Nurse practitioners - can do necessary monitoring, etc. - people with chronic disease don't necessarily need to see a physician
- Family - "journaling" of doctors' appointments, test results, follow-up, etc.
- Need to educate health care providers about visible and non-visible chronic diseases - provide rudimentary information
- Health Links/Info Santé - let people with chronic disease know what kind of resource this could be to them
- Could be volunteers - health educators/support to people

- Linking patients with others who have experienced the same chronic disease
  - Some people will need assistance to navigate the system - manage their condition
- 3. Considerations for Vulnerable Populations (living with chronic disease) and how they access primary care:**
- Age and mobility - difficulty getting to appointments, treatment, etc.
  - Arthritis, fibro-myalgia - getting out is very difficult, people with these and other chronic diseases can become very isolated, depressed, etc.
  - End of life care - treatment, pain management
  - Northern residents who come into the city for treatment - sometimes with family - placed in housing developments, etc. - have security issues, are fearful, etc.
  - Linguistic differences - newcomers - information is not in their language - they are less likely to understand their chronic disease, treatment and directions from care provider re: self-management
  - Follow-up after surgery/treatment - no support, assistance
  - Those living in poverty
  - Those with substance abuse issues - may not be able to understand how to manage their health condition
  - People with mental health issues - may make it more difficult to get care, manage condition
  - People living in poor housing - type of housing, may have accessibility issues - impacts on them - may not have access to mobility assists, etc. - need for better design to accommodate people living with chronic disease - need to understand disease processes and design accordingly
  - Lack of transportation
  - Children with chronic disease - how children are impacted emotionally, etc. - young children who end up caring for a parent with a chronic disease - inappropriate but happens
  - Need to consider those who do not have phones - 10% of the population - very poor - can't contact Health Links/Info Santé, etc.
  - Dietary considerations - malnutrition, in low income populations - difficulty accessing nutritious foods
  - Have breakfast programs at schools
  - "neighbourhood watch" - volunteer to check in on elderly, vulnerable neighbours - especially those without family

- Those living in fear - in neighbourhoods with high incidence of crime - need to address - some people won't leave their homes

## **Seven Oaks and Inkster Community Health Advisory Council – Second Meeting**

The following notes are from this Council's second meeting on chronic disease, Members provided input on the following question:

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

### **Language and cultural barriers**

- Educational barrier - cultural backgrounds may lead one to deny a chronic condition
- Linguistic and language barriers - not receiving care or information about the chronic disease in their first language - don't understand what the physician is asking them re: symptoms, etc.
- Could also have language barriers which increases the chance of miscommunication
- Cultural barriers - lack of knowledge by healthcare providers of culture and faith practices
- Language barriers - family members interpreting - miscommunication, lack of understanding
- Handling patients from different cultures - lack of ability of health care providers to do this
- Newcomers

**Communication between healthcare provider and patient/family** - this includes educational/literacy barriers

- Physician not listening/communicating well with patient - don't have good relationship with physician, may not even have a physician --- out patient, or walk-in clinics - won't spend time necessary for patient with chronic disease
- Communication barrier - from patient to health care provider (won't be taken seriously) - may not have the right words, ability to describe accurately what they are experiencing - body, mind, and spirit - don't have the vocabulary, may have memory issues -- won't be accurately diagnosed as a result
- Some people don't want to tell/disclose symptoms because they are embarrassed and/or afraid that people will know - that it will have a negative impact on them

- Language - communication problems when healthcare providers use medical jargon - speak in plain English!
- Competency and cognition issues - won't allow family member to accompany because of PHIA interpretation

**Lack of primary care provider or long term, supportive relationship with primary care provider** - includes attitude of primary care provider

- Judgement by some health care workers about the legitimacy of some chronic diseases - like fibro myalgia - minimizing a person's experience with a condition and not receiving adequate care as a result
- Lack of long term relationship with health care provider - not there - lack of continuity of care - impacts on treatment plan
- Some physicians are hesitant to refer to specialists - requires work, physicians may be reluctant - unsure if referral is necessary or not - some physicians don't like to refer
- Bedside manner of physicians - they need to understand the barriers that patients experience, be sensitive to them, and draw out information from patients by asking specific questions, etc. - they need to be trained to do this
- Lack of acknowledgement by health care providers that patients know their own body - physicians don't legitimize peoples' self-awareness of their chronic disease, symptoms, etc. - they can sometimes be arrogant, and intellectually superior, insensitive
- Inconsistency of follow-up

**Lack of knowledge/awareness about the chronic disease, treatment options, medication, etc.** (patient and family members)

- Lack of education and awareness of symptoms of chronic disease - should provide information in a variety of languages
- Not completing prescriptions - when patient starts to feel better, they stop taking prescription, or they don't like the side effects, so they stop taking them - prescriptions - to take or not to take --- is sometimes a decision about quality of life
- Taking multiple medications to counter the side effects of them
- Progression of a chronic disease - different levels of severity --- develop "path" for patient - what to expect at different phases, etc.
- Have mechanism to educate patient and family about the chronic disease, treatment plan, medication, follow-up appointments, etc.

- Education/literacy barriers - may have difficulty understanding diagnosis, treatment plan, etc.
- Lack of recognition of alternative therapies - often dismissed by traditional health care providers
- Forgetting treatment plan - not written down, not in their language

**Attitude about the chronic disease** - denial, stubborn and don't want to follow through, lack of motivation (especially when not seeing improvement), stigma, etc.

- Denial of a chronic disease also includes not knowing symptoms/recognition of symptoms - couldn't be me - minimizing
- Mental health - lack of understanding of disease process - misunderstanding
- Self management re: taking prescription/medication - especially if they have a mental health issue as well
- Pride, fear of alienation, reprisal (like HIV/AIDS)
- Stigma of chronic disease
- Stubborn attitude, refusal to try to manage condition

**Lack of support/advocacy** to assist with appointments, treatment, follow-through, etc.

- Following up with the treatment plan - family member who may need support to follow through
- Shutting down when you get a diagnosis - need someone to support you and ask questions of the physician
- Need for support when first diagnosed with chronic disease - following through/checking in on patient regarding progress and treatment plan until they are comfortable
- Family member not telling patient what disease they have to protect them
- Substance abuse

### **Income**

- Poverty - can't buy medication, nutritious food, etc.
- Lack of cooperation by non-government organizations like the workers compensation board and by insurance companies - lack of sensitivity towards patients with chronic disease

- Disability leave - disagreements re: a person's ability to work when they have a chronic disease
- Living in poor housing
- Malnutrition
- Safety barriers
- Lack of transportation

**Short appointment times, lack of follow-up, fee for service structure**

- Short appointment times - one symptom per visit - how can you get care when you have a chronic disease with many symptoms?

Prioritization of Barriers to Self-management of Chronic Disease --  
addressing the most significant barriers to self-management of chronic disease):

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.

Barriers ranked:

1. Lack of support/advocacy to assist with appointments, treatment, follow-through, etc. (12 points)
2. Language and cultural barriers (10 points)
3. Lack of knowledge/awareness about the chronic disease, treatment options, medication, etc. (patient and family members) (10 points)
4. Lack of primary care provider or long term, supportive relationship with primary care provider - includes attitude of primary care provider (7 points)
5. Communication between healthcare provider and patient/family - this includes educational/literacy barriers (6 points)
6. Attitude about the chronic disease - denial, stubborn and don't want to follow through, lack of motivation (especially when not seeing improvement), stigma, etc. (3 points)

7. Income (no points)
8. Short appointment times, lack of follow-up, fee for service structure (no points)

**Top Three Barriers:**

1. Lack of support/advocacy to assist with appointments, treatment, follow-through, etc. (12 points)
2. Language and cultural barriers (10 points)
3. Lack of knowledge/awareness about the chronic disease, treatment options, medication, etc. (patient and family members) (10 points)

Ideas for Addressing Top three Barriers to Self-management of Chronic Disease:

1. **Lack of support/advocacy to assist with appointments, treatment, follow-through, etc.**
  - Create advocate positions at the community level - (Access Centres and other WRHA Community Health and Social Services offices)
  - 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
  - Utilize volunteers with different languages to support and interpret during appointments, etc.
2. **Language and cultural barriers**
  - Use picto-grams and symptoms charts to assist with interpretation during doctors appointments, etc.
  - 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
  - Develop volunteer language pool for health care providers to call on - students (high school and university)

**3. Lack of knowledge/awareness about the chronic disease, treatment options, medication, etc. (patient and family members)**

- Provide information about chronic disease to children at schools, will share with parents, etc.
  - Increase profile of chronic diseases
  - Need to consider the potential anxiety this may cause for kids
- Work with Manitoba Health and fee for service doctors so that patients can receive summaries of doctors' notes every year
- Provide information in plain, simple language - eliminate medical jargon - especially information about prescriptions
- Provide journals to document treatment options, etc. - binders to keep information
- Provide handouts on treatment program, nutrition, exercise, etc., and on prescriptions and side effects
- Provide easy way to get information about how your medications interact - like encouraging people to go to the pharmacy with all of their over the counter and prescribed medications to discuss with pharmacist

## **St Boniface and St Vital Community Health Advisory Council – First Meeting**

The following notes are from this Council's first meeting on chronic disease, Members provided input on the following questions:

- What is chronic disease?
- 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?

### **What is Chronic Disease?**

- Determinants of health - people with vulnerabilities are more prone to getting chronic disease
- Aging population impacts this
- On-going
- Can be managed, treated
- Need to educate the general public about chronic disease
- Vulnerable populations that need to be considered especially
- Family history
- Prevention - need to know family history
- Environment can have additional impact on someone with a chronic disease
- When you have a chronic disease - it can impact your mental health, create depression
- Impacts on family members - spouse, children
- System is geared for dealing with acute health issues - people with chronic disease don't get adequate attention
- Genetic conditions

### **1. Improving Access to Primary Care Providers:**

- Dealing with "wait" times to access primary care health care provider or family physician
- Longer appointment times with doctor so that they can get to know patient
- Don't know how access to primary care works
- Knowledge of system currently is important so we can adapt/re-organize system to chronic diseases

- Should be able to access family physician immediately; involves triage to determine what the patient's needs are; assessment and evaluation that day so not going to ER; patient cannot make the decision as to what their needs are
- Public knowledge/education about what chronic disease is
- Each individual should have a primary care provider - how can an individual who does not have doctor get one? Should we prioritize those with chronic disease? And schedule appointments into the future (and maybe make it mandatory? Like appointments are scheduled for prescription refills - set future appointments for those with chronic disease
- Long term relationship with primary care physician/family doctor is important
- Primary care provider may not be able to accommodate patients with chronic disease - not accepting patients with chronic disease (they ask before accepting new patients)
- Doctor availability; when not optimal patients tend to go to walk-in clinics
- Lack of available doctors for populations with chronic disease - example, children and infants - lack of paediatricians
- Lack of access causes suffering (undue) to patients and causes patients to have to access walk-ins or emergency departments
- Insufficient time and resources
- System design is a factor
- Culture and belief systems are factors - individuals are also responsible for their own health; must educate and motivate and support an individual's ability to educate themselves about their disease and assist in their own health care
- Fee-for-service (with Manitoba Health) in question; do not go through WRHA unless they admit patients to hospitals, hospital privileges
- Communication among medical clinics (not just primary care providers) is essential as many patients visit multiple sites and may not be able to spot a chronic disease
- Clinics had doctors with appointments but also had hours for walk-in - nurse/nurse practitioner maybe available
- Booking only three days in advance
- Prioritization of chronic disease patients for quick appointments within clinics
- Change/focus re-design issues within education of healthcare workers (nurses and family practitioners coming out of school)

- Family Practitioner addressing prevention issues - a certain amount of health care funding should be directed here
- "Successful" clinics should have a venue to share how they deal with important issues in clinics and with patients
- Sharing data from research so it can be put into practice
- Not replacing retired primary care practitioners/family doctors - need more doctors
- Link between WRHA and doctors is very important; must work together
- Computer users and non-computer users will need access via different means/information
- Funding required/more directed towards nurse practitioners and physician assistants to assist family doctors - can we change the system to support this idea without having to add more money to it
- Re-design teaching strategy - French system
- Health Links/Info Santé - telephone for triage - access is beneficial and needs to be advertised more, can we use this to improve access for vulnerable populations?
- Tele-Health - (TV video-conferencing)
- Ease doctors concerns about loss of money when other healthcare professionals play a more integrative role
- One issue per visit for fee-for-service visit to primary care provider - this is a barrier to those with chronic disease
- Get information on access out to vulnerable populations
- Vulnerable populations don't know how the health system works
- Need to know the type of disease/rates of incidence - reorganize to adapt to the demand
- When calling doctors' office, everyone should be able to get in - screen/evaluate to see if their condition/status requires that they see the doctor - maybe a nurse could address - this could ease anxiety
- Better communication between walk-in clinics and family doctors
- Health records being able to be accessed - so you can see the patient's whole history
- Pharmacist - bigger role in care - great resource, source of knowledge
- "Chronic" - public doesn't know what this means
- "Not okay to not have a doctor. This becomes critical when you have a chronic disease."
- People with chronic disease should have priority - monthly, bi-monthly check-ups with family doctor

- Don't have to wait until something happens - have regular appointments
- Everyone needs a doctor
- People get doctors because of knowing someone
- Appointment to see if they would accept - wouldn't accept people with chronic disease
- Lack of paediatricians - would be a problem if child had a chronic disease
- Go to emergency - to treat acute symptom - but won't look at root causes
- Culture of medical profession - attitude, belief system
- Individual's need to take more responsibility to manage own health advocate for yourself, getting the information you need.
- Some people just need advice - what about re-directing to Health Links/Info Santé
- Redesign starts with medical and nursing schools

## **2. Chronic Disease Care Team:**

- Family knowledge of disease is important in order to support family member with chronic disease
- Website information sites for patients to access knowledge to bring to physician appointment
- Nurses, physiotherapists, occupational therapists
- Channels between walk-in clinics and family doctor so patient information can be transferred; improves access to family doctor - communication among medical professionals is key
- Pharmacists to play a more integrative role in health care especially when you have a history with them also
- Psychologist; psychiatrist
- Alternative health practitioners, naturopaths, acupuncture
- Nurse practitioners; midwives
- Individuals involved in prevention
- Traditional and alternative health practitioners working together
- Integration among healthcare professionals
- Nurse practitioners importance is overlooked - should give them more responsibilities to those individuals to take some of the load off of family practitioner
- Physician assistants
- Dieticians
- Fitness/health leaders and professionals
- Nurse

- Physiotherapist
- Occupational therapist

### **3. Considerations for Vulnerable Populations (living with chronic disease) and how they access primary care:**

- Infants, children due to lack of paediatricians
- Mental health issues for some individuals that require management
- Non-computerized primary care providers make some patients vulnerable
- Those with low socio-economic status
- Non-web/computer users, those who have difficulties accessing information
- Sending Health Links/Info Santé information and programs home with children through schools and community centres - also health care professionals to come and do presentations)
- Bringing health professionals of all types to low income schools, senior centres, Sialom Mission and other areas
- Seniors with memory issues
- Seniors and newcomers should have liaisons for health
- Immigrants - immigrate to isolated areas - community services that are available need to be communicated to these individuals
- Cultural community centres to address important issues with health care professionals that are culturally sensitive
- Those living with chronic disease are vulnerable just having a condition, as multiple issues create barriers for being able to access primary care (one issue per visit)
- People living with Alzheimer's

## **St Boniface and St Vital Community Health Advisory Council – Second Meeting**

The following notes are from this Council's second meeting on chronic disease, Members provided input on the following question:

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

### **Mental health conditions, like depression**

- Mental health - lack of motivation and/or not enough support
- Depression
- Mental health issues/conditions like obsessive compulsive disorder - difficult to diagnose
- Feeling of loss of control, feeling that you are the disease - need more information about their chronic disease

### **Lack of motivation, support, taking responsibility for and lead in managing chronic disease**

- Lack of motivation
- Not just the physician's responsibility to solve your health problems
- The very elderly - very dependent on family members for support to retain quality of life
  - Those without that support - their health can fail, quality of life is much worse
  - Elderly abuse in some homes - financial, physical, etc. - addressing this needs to be driven by compassion
- Gender - men are more resistant to going to the doctor - they procrastinate
- Aging - need to do some self-diagnosis, need to know yourself, your body, need to care for yourself
- Need to acknowledge that a chronic disease could have a range of severity in people - from not too ill to very ill
- Checklist for following treatment plan, self-care, taking medication, etc.
- Cultural dependence on experts to take care of us
- We need social support

### **Lack of integrated, coordinated, holistic and patient-focused health care system**

- Lack of access to health care services - evenings, etc.
- Lack of holistic approach
- Insufficient use of other health professionals - like nurses, nutritionists, health practitioners, etc.
- Delay in diagnostic tests after initial appointment - months...is this necessary? Should be more accessible. Are there other MRI's available sooner?
- Lack of follow-up after hospital stays, etc. by family physician
- PHIA could get in the way of sharing between health care providers - problems with interpretation of the act, acting on the best interest of patient, confusing - health care workers fearful of being fired if they provide information
- Improper assessment - initial diagnosis of a condition becomes a lengthy process - like Multiple Sclerosis
- Insufficient use of on-line therapies - like therapy for people with mental health issues
- Health care system - not focused on patient - it is system-focused right now -- illness-focus instead of wellness-focus
  - Power/control should rest with the patient, not the health care provider/system
  - Holistic approach is missing
- Lack of integration of health services - "try prescription...if it doesn't work...see physiotherapist, if that doesn't work...."
- If chronic disease is really addressed, it seems that physicians would need to have to give up something
- Waiting period can be a barrier - waiting for results from tests
- Prescription medicine - side effects - quality control should ensure that cure is not worse than disease

### **Language and cultural barriers**

- Language barriers - have dvd's in different languages about chronic diseases
  - Growing French population here - not enough health care providers in French, not enough resources to meet the increased demand - three year wait for Francophone specialist
  - Family members translate

- Patient won't understand diagnosis, treatment options, self-care instructions, etc. from doctor when there is a language barrier
- WRHA has language access program - interpreters who work with patients - direct translation in 23 languages
- Cultural barriers - multi-cultural environment - different processes and procedures in their countries of origin than in our system - need to explain how our system works to newcomers
  - Muslim women, for example, need to be treated in culturally appropriate way, certain procedures that they are not comfortable with
  - Health care providers need to know how to deal with different cultural groups

**Lack of knowledge, health literacy, and access to information about chronic disease, treatment options, and resources**

- Lack of access to health care records - if you don't know your history, how can a treatment plan be developed?
- Lack of sufficient information on their condition, self-care - or easy access to
- Lack of knowledge of coping strategies
- Insufficient knowledge of alternative strategies and therapies to treat their chronic disease
- Lack of information about resources - people then do not access them
- Lack of health literacy - not knowing what is wrong with you, also, some physicians may lack thorough knowledge some chronic diseases - may not know of all treatment options available, steps to managing the chronic disease
- Physician's lack of understanding of scope of resources, etc. for chronic diseases

**Poor communication with and relationship with health care provider**

- Need to have the courage to ask questions, get information on your diagnosis, etc. - you need to have that information in order to self-manage your chronic disease
- Might be hard for health care professionals to deal with educated, assertive patients - medical professionals haven't kept up with this
- Doctor know best approach - arrogance - is a huge barrier

### **Income barriers**

- Income barriers - the lower the income, the less able someone is able to find a solution - can't access some programs, experience transportation barriers, difficult to buy nutritious food, etc.
  - May impact self-esteem, ability to cope, ability to purchase prescriptions
- Not having a phone and trying to communicate with health care providers - frustrating, a barrier - getting the run around, can't answer simple questions, don't know who to call

Prioritization of Barriers to Self-management of Chronic Disease - addressing the most significant barriers to self-management of chronic disease):

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.

### Barriers ranked:

1. Lack of knowledge, health literacy, and access to information about chronic disease, treatment options, and resources (15 points)
2. Language and cultural barriers (11 points)
3. Lack of integrated, coordinated, holistic and patient-focused health care system (10 points)
4. Poor communication with and relationship with health care providers (10 points)
5. Lack of motivation, support, taking responsibility for and lead in managing chronic disease (9 points)
6. Mental health conditions, like depression (5 points)
7. Income barriers (4 points)

### **Top Three Barriers:**

1. Lack of knowledge, health literacy, and access to information about chronic disease, treatment options, and resources
2. Language and cultural barriers
3. Lack of integrated, coordinated, holistic and patient-focused health care system

### **Ideas for Addressing Top four Barriers to Self-management of Chronic Disease:**

- 1. Lack of knowledge, health literacy, and access to information about chronic disease, treatment options, and resources**
  - Develop support groups for people with chronic diseases
  - Give patients access to their medical records
  - Simplify the medical terminology - have health care providers communicate in plain, simple language about the chronic disease and treatment options, etc.
  - Create a task force of doctors - to develop plan about how to educate the public about chronic disease
  - Have a public information campaign about chronic disease - one per month
- 2. Language and cultural barriers**
  - Train health care providers in cultural safety/social accountability - use mentors
  - Hire more doctors with diverse backgrounds - focus on Francophone
  - Create written translated information about chronic diseases
  - Train more interpreters in languages currently not provided - expand the language access program
  - Inform staff and the greater public about cultural awareness
  - Utilize social and cultural associations across the city - engage and partner with them to educate and provide services to address chronic disease -- to culturally diverse populations
  - Educate Newcomers about our health care system
- 3. Lack of integrated, coordinated, holistic and patient-focused health care system**
  - Use access centre model to reach vulnerable people

- Utilize better diagnostic tools
- Develop team approach to care and management of chronic disease
- Public awareness campaign about the importance of asking questions of your health care providers and taking control of your chronic disease care plan
- Train doctors in the holistic approach - mental health as well as physical and of the importance of engaging patients, good communication, etc.

## **St James-Assiniboia and Assiniboine South Community Health Advisory Council – First Meeting**

The following notes are from this Council's first meeting on chronic disease, Members provided input on the following questions:

- What is chronic disease?
- 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?

### **1. Improving Access to Primary Care Providers:**

- There is a level of personal responsibility when one has a chronic disease in terms of accessing the care that one needs
- Family doctors need to get consults when they're not sure/don't have experience dealing with certain chronic diseases
- Not everyone can advocate for themselves
- People should be able to access - list of tests that could be done to diagnose certain chronic diseases - people should be persistent
- Make doctor's appointments effective - go prepared, write down what's happening, questions, etc.
- Issues for people coming into Winnipeg - no doctor, prescriptions running out
- Have form to fill out at doctors' offices - symptoms, objectives of appointment, etc.
- Multiple Sclerosis clinic
  - Can access very quickly, if condition worsens
  - Strategize, change/modify medications, address stress
- Have the ability to email a nurse practitioner if something happens, they can respond, without appointment
- Use technology for care/treatment program and management of that person's care, connect with health care provider, "account" with your information - treatment, diet, etc. - "virtual chronic disease management"
- Phoning/faxing doctor - (process is created to allow chronic patients to connect with doctors about some issues of their care)
- Family doctors creating balanced mix of patients - not all with complex health needs

- Keep a certain percentage of appointments open per day for emergencies
  - patients must fit certain criteria - re: have chronic disease with worsening conditions that need to be addressed immediately or patient will end up in ER
  - Would need to educate physician office staff about criteria and process, etc.
- Need more doctors!
- Need better overall management!

## **2. Chronic Disease Care Team:**

- Nurse practitioners
- Computer program to list treatment for chronic disease - will refer to document when needed
- nurses - lots of experience dealing with chronic illness - like at personal care homes
- body, mind, spirit - all need to be addressed
  - Nutritionist
  - Mental health specialist - give patient support before depression, anxiety set in
  - Spiritual care
  - Support groups for the condition?
  - Psychologist
  - Dietician
  - Occupational therapist
  - Pain management specialist
  - Physiotherapist
  - Naturopathic doctor
  - Chiropractor
- Should work with associations for chronic diseases - family doctors can utilize - info, resources - that they should link, partner with, work together
- Need for sharing - the willingness needs to be there - between providers caring for same patients
  - Lab results, etc. - hospitals should share with family doctors - i.e. logging into program to get info on a patient
  - Getting copies of lab results to patients
- Team needs to be well informed and open to working/collaborating together

- Use other teams as benchmark - "chemotherapy team", etc.
- Use clinic approach
- Provide assistance with disabilities insurance, financial issues - chronic disease associations can provide assistance with this

### **3. Considerations for Vulnerable Populations (living with chronic disease) and how they access primary care:**

- Newcomers don't have family doctors, what then? End up going to emergency department when chronic disease is not managed
- Need for mental health support
- Need to be able to talk to someone in their own language
- Need to consider traumatic issues
- Language barriers
- Need to consider those people who have difficulty keeping appointments - are there other options for them? (could be mental health issue, transportation issues, no phone, moved, etc.)
  - Shorter time frame for appointments would help (not 3 months later, within the same week)
- Need advocates for those who need support to manage their disease, get to doctors' appointments, etc.
  - Potentially, a social worker could carry out this role
- Need to consider where clinics are located
- Access centres - use for chronic disease clinics - could be scheduled in bi-weekly, etc.
- Communications - in a variety of languages, need to consider how the information is communicated, ensure that there is understanding
- Consider literacy issues
- Need good education about their chronic disease and understanding of their role in managing it, treatment, and what happens if treatment plan is not followed

## **St James-Assiniboia and Assiniboine South Community Health Advisory Council – Second Meeting**

The following notes are from this Council's second meeting on chronic disease, Members provided input on the following question:

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

### **Lack of timely access and awareness of resources and treatment options (also, attitude that only doctors can treat chronic disease)**

- Long waits between doctor and specialists appointments
- Lack of access to the services you need when you need them
- Reliance on doctors, specialists and the belief that only doctors can address issues - should be open to others - need for a different approach, 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
- Lack of basic knowledge and awareness of services, resources, etc. that are available - like Alzheimer's Society, Cancer Society, MS Society, etc.
- Family doctor/primary care provider may not be aware of resources, etc.
- Chronic disease associations are run by volunteers, have little funding - a clearinghouse approach would be good
- Referral process - having to repeatedly go back to family doctor for referrals to specialists - dieticians, etc - could be better use of health resources and more timely
- Lack of a family doctor
- Not engaging other care providers - nurses - who have a lot of experience treating chronic diseases
- Some people may find it difficult to understand complexities of their chronic disease, treatment plan
- Having to go to multiple appointments all over the city

**Lack of support and advocacy, understanding and acceptance** (family, friends, employer, doctors, society, insurance companies, etc.) - create resources to build understanding, etc.

- May not have a family member/friend to support you and advocate for you

- Lack of supportive employer - not allowing time off for medical appointments, sick days, etc.
  - Not understanding that person with a chronic disease will have really bad days from time to time
- Family/friends not included in treatment plan/care approach
- Supportive family is not necessarily an "accepting" family - chronic - this is not going away - need flip in attitude towards the chronic disease and the family member
- Insurance coverage - chronic disease disputed by insurance company - need for assistance to fill out forms, etc.

**Lack of income/benefits** - Pharmacare, pension, disability coverage, can't afford nutritious food, etc.

- Lack of Pharmacare coverage for some prescriptions and medical equipment
- Lack of income, poverty
- Lack of or difficulty with disability coverage - insurance claims, etc.
- Lengths of time you need to work before you can make a claim

**Mental health challenges** - depression, anxiety, denial of chronic disease, lack of compliance

- Anger experienced - about the chronic disease, longing for the life before you got sick - part of overall mental health aspect
- Denial of condition, refusal to be part of treatment/care
- Mental health issues as a result of the chronic disease - depression, anxiety - can create additional barriers
- Those who may be experiencing other issues - like addiction
- When you have been ill for more than six months - not being taken seriously, feeling of abandonment, that it is a mental health issue not physical
- The amount of energy it takes to be compliant with your treatment plan - diet, exercise, medication, self-monitoring, etc. - takes a lot of energy, even if you're up for it

**Lack of mobility**

- Mobility - not having transportation, difficulty getting to appointments
- Condition itself is limiting - can't get out for nutritious groceries, get to doctors' appointments

**Communication barriers** - language, literacy, information is too complex, impairment caused by chronic disease

- Literacy challenges - not being able to read educational materials, etc. about their chronic disease
- Language barriers - not having services offered in own languages
- Communication barriers - not being able to communicate what you're feeling, your condition (those who have had strokes, etc.)
- The feeling that no one listens - especially to the elderly - physician visits personal care home one morning per week to provide care to the most acutely ill - staff are completely overwhelmed with so many residents with chronic disease

Prioritization of Barriers to Self-management of Chronic Disease - addressing the most significant barriers to self-management of chronic disease):

\*This Council chose not to prioritize the barriers but instead to identify those barriers that they felt that the WRHA could address

1. **Lack of support, compassion, advocacy and need to address communication barriers** - need for broader acceptance, need for advocacy/support, need for materials in multiple languages and in simple language, need for interpreters
  - People need to know that they can get an advocate, can hire an advocate
  - Should be more public awareness about chronic diseases - and linking with chronic disease associations to provide information and support to patients and families - WRHA should be encouraging people to use these organizations
    - Doctors, nurses, etc. should refer patients and families to these chronic disease associations
  - List information and links to chronic disease associations on the WRHA website
  - Have Health Links/Info Santé - provide information about the chronic disease associations as well to the public
    - Have information also available to be picked up at Access Centres for those without internet

- Need alternative approach to internet - clinic/counsellor to direct people to resources/share information - outreach to people with chronic diseases
- Hold a chronic diseases campaign like the breast cancer campaign - to increase public awareness of chronic disease - what role could the WRHA play in this?
- Need to address language barriers - 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, increased utilization of language access program interpreters, engage volunteers from different cultural groups to assist - advocacy, support, and interpretation

## **2. Mental health issues**

- Further develop peer support groups for people with chronic diseases - could work in partnership with chronic disease non-profit groups
- Include mental health counsellors/supporters as part of the clinic/team approach - include patient's supports in peer support and overall treatment program - families and friends who can then further support them - need to recognize how hard a chronic disease can be on the patient's family
- Should have a holistic approach - body, mind, and spirit to treatment of chronic disease - mental health, diet, exercise, stress management, alternative approaches, pharmacist to assist with prescription/medication issues
- Need to develop approach to treating/providing services to people with chronic disease who also have addictions issues
- Include peer support/chronic disease non-profit groups as part of the chronic disease care team - not just medical professionals
- 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
- Ensure that pharmacists are included in the chronic disease care team approach

- 3. Awareness of and access to health services treatment options, etc. and openness to other treatment approaches**
- Develop alternative to referral system - development of short-track referrals so that once you've been referred to a specialist (for your chronic disease) you don't have to go back to your physician in order to see them again - once a diagnosis has been confirmed
  - Development of a clinic/team for "Top 8 chronic diseases" - where you can utilize best practices, have website, etc. - link these clinics with the appropriate chronic disease associations
    - Physically - locate appointments, specialists together - same location, same day - include pharmacists
    - Could have multiple locations for these clinics
    - Model for this approach already exists - arthritis, tuberculosis, etc. - or, like the mature women's clinic at Victoria General Hospital
  - Work with other regional health authorities to create chronic disease clinics outside of Winnipeg - would have to be Manitoba Health led

# Appendix A

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

<b>Council</b>	<b>Barrier #1</b>	<b>Barrier #2</b>	<b>Barrier #3</b>	<b>Barrier #4</b>
<b>Downtown/Point Douglas</b>	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
<b>River East/Transcona</b>	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	
<b>River Heights/Ft Garry</b>	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
<b>Seven Oaks/Inkster</b>	Lack of support and advocacy	Language and Cultural Barriers	Lack of knowledge/ awareness of chronic disease and treatment options, resources	
<b>St Boniface/St Vital</b>	Lack of knowledge/ awareness of	Language and Cultural Barriers	Lack of Integrated, coordinated,	

<b>Council</b>	<b>Barrier #1</b>	<b>Barrier #2</b>	<b>Barrier #3</b>	<b>Barrier #4</b>
	chronic disease and treatment options, resources		holistic and patient-focused system	
<b>St James/ Assiniboine South</b>	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

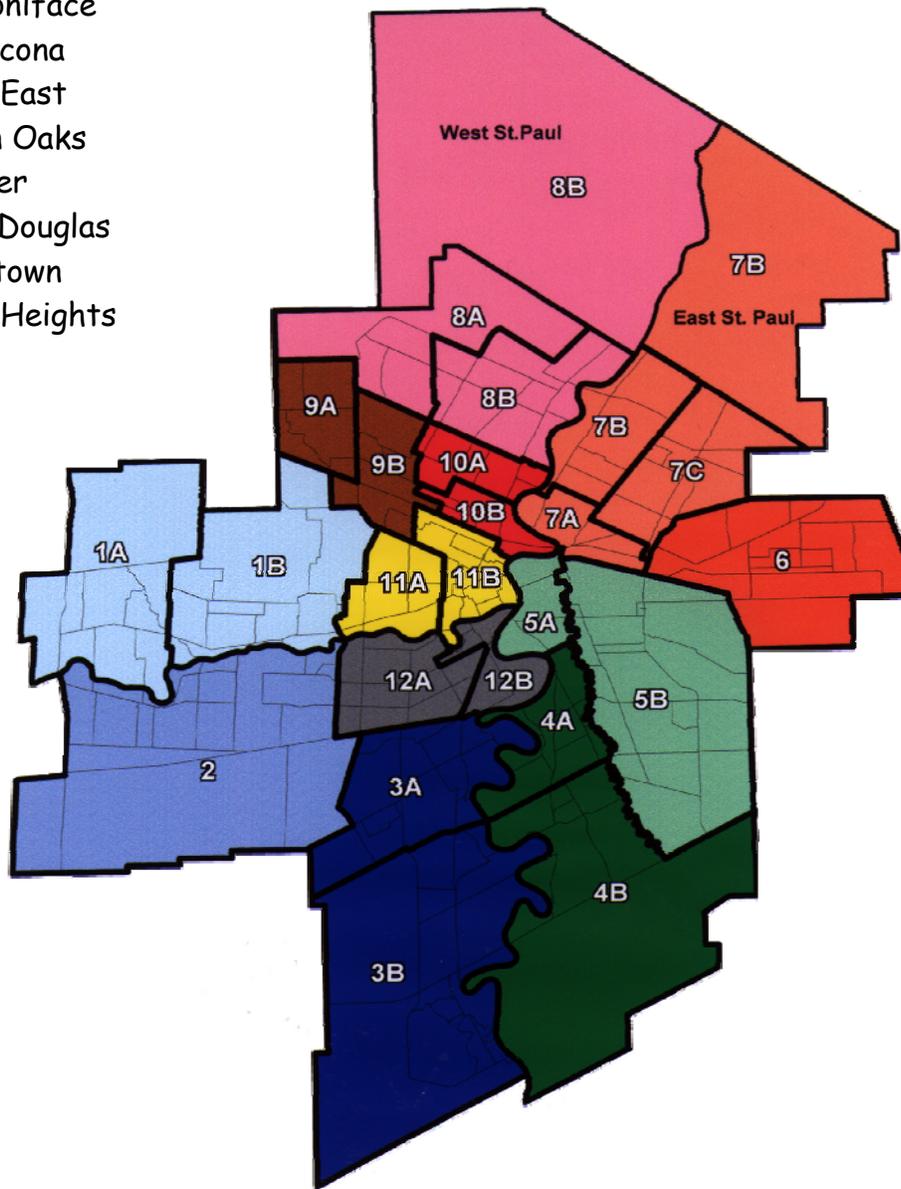
Number four: Language and Cultural Barriers

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 Juseslius	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**

Nicholas Chubenko  
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**

Bathelemy Bolivar  
Rene Fontaine  
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**

Gary Attenborrow  
Erika Barton  
Lynda Collins  
Cara Katz  
Carol Loader  
Alison McKay

Brian McMillan  
Ally Mironiuk  
Nancy Nagy  
Angela Tessier  
Patricia Winton  
Paul Zubec

### **Volunteer Assistants to Councils**

Rachelle Mousseau	Downtown/Point Douglas
Rishi Srivastava	River East/Transcona
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

### **Support Staff for Councils**

Jeanette Edwards	Regional Director, Primary Health Care and Chronic Disease
Suzie Matenchuk	Manager, WRHA Volunteer Program
Sylvie Pelletier	Administrative Assistant
Colleen Schneider	Manager, Community Health Advisory Councils