North Simcoe Muskoka **LHIN**

Directions from a Local Scan: Self-Management and Empowering the Person Living with Diabetes in the North Simcoe Muskoka LHIN

November, 2009

Ontario
Local Health Integration Network

EXECUTIVE SUMMARY

DOCUMENT SCOPE

This document is a summarized version of local health status on chronic conditions and findings from a report completed by a member of the North Simcoe Muskoka Chronic Disease Prevention and Management Regional Action Group. The report provided a local scan on diabetes and self-management practices and resources in North Simcoe Muskoka.

The objective of the scan was to provide the North Simcoe Muskoka Local Health Integration Network (LHIN) an overview of the current state of diabetes practices and resources to inform planning in support of the roll-out of the provincial diabetes and eHealth strategies. This summary highlights the findings and recommended directions out of the local scan. Findings from local and provincial dialogue reflected support for the integration of self-management across the continuum of care. These recommendations lay the foundation for the North Simcoe Muskoka LHIN Integrated Health Service Plan (IHSP) priorities, which are:

- **Improving chronic disease management, beginning with access to integrated diabetes care,**
- **Improving access to appropriate care, beginning with the emergency room and alternate level of care settings in the community or home, and**
- **Creating an integrated design for the future health system in North Simcoe Muskoka.**

Overall, 18 recommendations were outlined to support an integrated approach to self-management in North Simcoe Muskoka. The recommendations reflect the following themes:

- The value and need for human capital infrastructure and resources in the diabetes field;
- The implementation of self-management support across the continuum of care;
- Leverage of self-management resources to support an integrated model;
- Ongoing engagement of specialists, physicians and consumers;
- The identification of critical success factors for providers and patients to be supported in the uptake of self-management practices and navigation of the health system;
- Standardization and validation of tools to yield information consistency and quality of diabetes care; and
- Knowledge transfer opportunities to support professional development and common language amongst health service providers.

In conclusion of the local scan, the following perceptions were emphasized to the LHIN in support of informing next steps in the coordination of diabetes stakeholders and services:

- A local diabetes stakeholder network is integral in overseeing diabetes management and service expansion/access in the region and could facilitate recommendations to the North Simcoe Muskoka LHIN, local stakeholders and a broader chronic disease network.
- A local self-management task-group would identify strategic directions towards the implementation and work plan development of the integrated self-management approach.

BACKGROUND

North Simcoe Muskoka LHIN

The Local Health Integration Network is working with community partners to improve access to integrated diabetes care to help people be better supported in the self-management of their diabetes.

Chronic diseases account for 55% of all health care costs in Ontario. The costs for North Simcoe Muskoka are expected to rise as our population ages and the number of people living with chronic disease increases. In North Simcoe Muskoka, diabetes prevalence in 2007 was 6.8% for residents over 12 years of age, compared to Ontario at 6.1%. Furthermore, prevalence in residents 65-74 years of age was 16.5% or 5,760 individuals.[1] This concludes that the number of residents living with chronic conditions such as diabetes, arthritis and hypertension has increased and has remained higher than the provincial level.

In 2005, North Simcoe Muskoka had more women (6%) diagnosed with diabetes than men (5%). While the rate for women has stayed the same from 2005 to 2007, the male rate had risen to 8% in 2007. Additionally, the presence of multiple conditions increases an individual's total burden of illness and the burden on the health care system. These individuals tend to experience longer hospital stays, greater associated health care costs, increased hospital mortality and higher rates of readmission to hospital.

The Ontario Diabetes Strategy

Ontario's Chronic Disease Prevention and Management Framework was developed and implemented as a comprehensive and integrated approach to dealing with chronic disease. Personal skills and self-management support is one of the components within this overarching Framework.

To complement the Framework, the Government of Ontario announced the Ontario Diabetes Strategy on July 22, 2008. This is a comprehensive strategy with $741 Million committed over four years to prevent, manage and treat diabetes. Ontario's Diabetes Strategy will help tackle a growing and expensive health care challenge. The number of Ontarians with diabetes has increased by 69% over the last 10 years, and is projected to grow from 900,000 to 1.2 million by 2010. Treatment for diabetes and related conditions such as heart disease, stroke and kidney disease currently cost Ontario over $5 billion each year. The strategy will support Ontario's two top health-care priorities of improving access to care and reducing emergency wait times.

The Diabetes Registry and Provincial eHealth Strategy

The Ontario Diabetes Strategy includes an online registry that will enable better self-care by giving patients access to information and educational tools that empower them to manage their disease. The registry will also give health service providers the ability to easily check patient records, access diagnostic information and send patient alerts.[2] This

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[1] Ministry of Health and Long-Term Care, CCHS Cycle 4.1, 2007

[2] Ministry of Long-Term Care- News Release- Ontario Launches Diabetes Strategy, July 22, 2008.

particular self-management tool is critical in diabetes management; however, adoption of the registry is dependent upon users having an understanding of the benefits of self-care and self-management. It is important that health system partners work collaboratively to enable the utilization of the diabetes registry by individuals living with or at risk of diabetes.

Directions in North Simcoe Muskoka

Through the work of the North Simcoe Muskoka Chronic Disease Prevention and Management Regional Action Group and the Self-management Workgroup, a model was proposed in support of regional access to a self-management program. Through local dialogue and a survey, it was recognized that diabetes stakeholders currently provide services complimentary to self-management programs and diabetes education. This recognition lead to the inquiry as to where and how individuals, who do not access self-management programs, prepare themselves to be active self-managers. Self-management practice and readiness will enable the successful adoption of the diabetes registry in support of the roll-out of the provincial eHealth Strategy.

In light of this recognition, how individuals currently are engaged in and have access to self-management programs needed to be further explored. This exploration lead to the examination of where other opportunities, programs and services exist if an individual does not attend a formal *program*. This analysis would inform the development of an integrated approach to self-management and identify where service delivery is intersected across the continuum of care for individuals. This identification would be helpful to facilitate opportunities for individuals to access self-management initiatives or supports. This broader approach to self-management encourages the people who may never attend a formal *program* to take charge of their own health.

Conversations with local residents and service providers across all five geographic areas of North Simcoe Muskoka were conducted in the compilation of this scan. This local knowledge and experience allowed for a better understanding of the overall self-management practices that are currently embedded into the work of health service providers and how these practices empower people living with diabetes to become self-managers.

Project Focus

Connecting with health service providers from different settings to get their perspective of self-management in relation to diabetes care and management was the focus of this initial work. The information gathered over the past two years by the North Simcoe Muskoka Chronic Disease Regional Action Group (i.e., diabetes survey) and research done by the LHIN was reviewed and incorporated appropriately as part of this project.

Local Engagement

Various stakeholder audiences were targeted to discuss self-management as it relates to diabetes. These targeted audiences included primary and secondary diabetes service providers (i.e., Diabetes Education Programs / Centres, Family Health Teams, the North Simcoe Muskoka Community Care Access Centre, Barrie Community Health Centre, and various Community Service Agencies). There were 43 different stakeholders contacted as a result of the local scan.

Throughout North Simcoe Muskoka, as of June 30, 2009:

- 8 organizational meetings and interviews were conducted,
- 16 key informant meetings / interviews were completed, and
- 5 programs outside of the LHIN were contacted and interviewed.

LOCAL FINDINGS

Self-Management in North Simcoe Muskoka

- All health service providers interviewed provided some form of self-management interventions. In particular within diabetes programs, patient education programs were the major focus with goal setting and when appropriate referrals were made to exercise programs in the community and support groups.

- Those interviewed were committed, passionate and caring individuals. Providers strongly supported patient self-management and have created innovative approaches to encourage self-management uptake in their communities.

- Providers were interested in receiving additional opportunities to learn about stages of change, self-management, brief clinical intervention, motivational interviewing and the many concepts related to empowering the patient to take charge of their own health.

- Literature, tools and resources are also effective ways to reinforce self-management. Many of the people interviewed shared and provided examples of what they use within their scope of practice.

- Providers explained that the people living with diabetes attend diabetes education programs and that many concepts of self-management were embedded in their programs. It was noted that funding models and limited human resources challenge providers' capacity to fully implement self-management supports.

- It was cautioned as to the assumption that that all people living with diabetes would attend a diabetes education program. For patients, evidence shows the effectiveness of self-management. However, for many reasons some people are not able to participate in self-management due to physical and / or psychological barriers. A huge challenge faced by those who do not have a family physician / primary care provider is how to be aware of and access the self-management supports needed.

- Pending the development of a diabetes registry and standardized practices / reporting, it is difficult to identify accurately the number of residents in North Simcoe Muskoka living with and at risk of diabetes and where they are accessing services and supports.

- There needs to be support for health service providers to embed the role of enabling individuals to effectively self-manage into regular practice. This is a major cultural shift for providers from a provider being in charge of the patient to empowering the patient to take charge of his / her own health. This will require a plan to educate and support this "shared care" ideology. It has been an assumption that providers have had the time to implement and the training to understand self-management supports when in fact this may be the reality for a small number of providers in North Simcoe Muskoka.

Challenges and Areas of Need Identified

Challenges identified through the local scan are provided as follows:

- Patients without a family physician / primary care provider do not have an entry point to a patient-centered multidisciplinary setting;
- With different funding and staffing models there is a lack of standardization of practice;
- There is a need for more comprehensive multidisciplinary teams for diabetes management across all geographic areas in North Simcoe Muskoka. Diabetes Management Centres currently have funding for Registered Nurse (RN) and Registered Dietitian (RD) positions. Expanding these teams to include positions such as: psychiatry / psychology, social work, physiotherapy, recreation therapy, podiatry / chiropody, pharmacy, and optometry / ophthalmology would fill the gap in resources to support individuals living with diabetes.
- A long wait or transit to specialists exists;
- A social services link with diabetes management education would be beneficial to provide hands-on, life care skills;
- Timely access to mental health services and follow-up is needed;
- People receiving community / home care services usually do not have access to Certified Diabetes Educator (CDE) staff;
- A gap exits in training and consistent messaging for providers practicing outside the direct care of diabetes;
- Increasing wait lists due to complex caseloads requiring longer visits / interventions;
- There is a shortage of health human resources, including certified diabetes educators and specialists;
- Information and further education on self-management supports is needed;
- Training and education for family physician needs to be provided to ensure effective and timely management of patients with diabetes;
- Perception that the referral of patients for diabetes education may not be occurring until complications arise;
- No short-term and long-term standardized performance indicators exist;

- Formal provider collaboratives for diabetes care all geographic areas in the LHIN like that of the Barrie and Area Primary Care Collaborative;
- Lack of a coordinated information and referral system to self-management programs / services and diabetes management system;
- Gap in diabetic care for young people living with diabetes who are attending post secondary educational institutions away from their main health service providers;
- People with end stages diabetes (palliative) to receive the appropriate support;
- Within Diabetes Education programs outside of family health teams, yearly follow up and patient recall is difficult to maintain due to lack of time and appropriate recall mechanisms;
- There is not a Regional Diabetes Network of stakeholders to share best practices and learnings; and
- There is a lack of formalized integration of chronic disease management programs (e.g., diabetes, nephrology, and cardiology). Vascular health initiatives and vascular secondary prevention serves diabetes as well (cardiac rehabilitation and stroke clinics).

Proposed Next Steps

1. Establish a Regional Diabetes Network that works in conjunction with the Chronic Disease Management Regional Action Group. This network will focus on achieving the goals and outcomes associated with the LHIN IHSP priority of improving chronic disease management, beginning with access to integrated diabetes care. The network will leverage current relationships, program and services in North Simcoe Muskoka. In each geographic area in North Simcoe Muskoka the development of a local diabetes collaborative will be established. These local collaboratives will partner with the Regional Diabetes Network and Regional Diabetes Coordination Centre.
2. Implement the integrated self-management supports approach through the development of action plans to achieve identified targets and outcomes. Identify funding opportunities for the implementation of the Regional Chronic Disease Self-Management Approach and in particular funding for a Regional Self-Management Program and the Brief Clinical Intervention / Minimal Contact Intervention or 3-Minute Empowerment tools.
3. Share the North West LHIN's Self-Management webinar to providers in this LHIN as an introduction and education session for self-management.

ACKNOWLEDGEMENTS

The information gathered for this project was from a number of valuable sources. The time taken by these many individuals is gratefully acknowledged and demonstrates their commitment to people living with and at risk for diabetes.

Appreciation and recognition is given to Monica Menecola as the Diabetes Project Lead for the North Simcoe Muskoka LHIN from April to July 2009. She is a member of the North Simcoe Muskoka LHIN's Chronic Disease Prevention and Management Regional Action Group. Her contributions and stakeholder engagement initiatives to inform the local scan are foundational to moving forward successfully in improving diabetes management in North Simcoe Muskoka.

RECOMMENDATIONS

1. Establish a comprehensive Diabetes Network (and Diabetes Collaboratives in each geographic area) in North Simcoe Muskoka to build on the current work of diabetes care.

2. Develop and implement five local area Diabetes Collaboratives where there is not a current collaborative structure in place. One of the purposes of these groups would be to develop diabetes care pathways and approaches to navigate the local health care system. This pathway of care will enable system navigation for various populations residing in North Simcoe Muskoka (e.g., patients without a family physician, family health team / non-family health team roistered patients, individuals with gestational diabetics, etc).

   The local area collaboratives will ensure consistency and coordination in service delivery thus ensuring individuals are supported to manage their own care where appropriate. These collaboratives will leverage and build upon the existing capacity and diabetes care and management services. Opportunities will be explored for integration of programs, services and system resources.

   The Diabetes Collaboratives should expand their outreach and link to professionals from the social service and community service areas to ensure that a more holistic approach to patient-centered care is adopted. Build on service partnerships and current networks.

3. Development of a subgroup of the Diabetes Network will be required to look at performance measures for improvements and evaluation processes.

4. Implement the Regional Self-Management and Supports Approach through the development of action plans. Identify funding opportunities for the implementation of the Regional Chronic Disease Self-Management Approach and in particular funding for a Regional Self-Management Program and the BCI/MCI project.

5. Identify individual local and regional champions of self-management that will move the principles of self-management forward. Leverage the knowledge of local self-management champions, local physician lead and local health care professionals.

6. Engage people living with diabetes to see who is assisting them with managing their diabetes and supporting them with self-management. This information will build on the self-management supports and interventions and where to set priorities for action.

7. Engage family physicians around self-management strategies and their role in implementing. Look at models such as the Chronic Condition Self-Management Guideline for General Practitioners Working with Chronic Conditions from The Royal Australian College of General Practitioners.

8. Provide education and professional development opportunities to promote the integration of self-management support to professionals. Organize training opportunities about self-management, the stages of changes and how it can be embedded in services offered by stakeholders. Facilitate knowledge exchange / transfers; communities of

practice; communication / support and mechanisms around self-management for health service providers.

9. Adopt or develop a toolkit to educate health care professionals and volunteers running support groups about self-management. An example of this would be the one developed by the South West LHIN.

10. Review, evaluate and adopt a regional diabetes toolkit for patients such as the one developed by the Diabetes Management Team at Barrie Community Health Centre. Develop a plan to create and produce this toolkit.

11. Establish an information / resource system that would include a website and 1-800 number (similar to information provided by searching 2-1-1 website for "Falls Prevention Initiative in Simcoe/Muskoka"). This mechanism will assist with system navigation for diabetes services, resources and community services for people living with diabetes and their families and for service providers. This would be a central repository that would list all diabetes services and include all layers of services available (e.g., specialists, optometrists, pharmacists, etc.).

12. Work with the Aboriginal Community to partner for culturally sensitive self-management supports and programs.

13. Use technology (virtual patient forums, on-line learning, virtual support groups, telehealth, etc.), as a means to reach out to people and make self-management programs and supports accessible.

14. Compile a comprehensive list of support groups in North Simcoe Muskoka. Self-management training opportunities can be shared with this group. This information can be used by providers.

15. Compile a list of local community-based self-management program trainers in North Simcoe Muskoka.

16. Development of innovative and equitable approaches to make self-management available to everyone.

17. Roll-out diabetes specific education and training for health professionals and services associated with this disease. An example of this is the cross sharing and training as the Central LHIN did with the Canadian Diabetes Association and Canadian National Institute for the Blind. Include, end of life care and mental health cross training.

18. Advocate for change in the current funding model for Diabetes Education and Management Centres.