

North Simcoe Muskoka **LHIN**

Community Engagement Sessions in North Simcoe Muskoka

August 2014



Background and Objectives

The North Simcoe Muskoka LHIN hosted six community engagement sessions in August 2014. The sessions, titled “Join the Conversation about Health Care in Your Community” were hosted in Midland, Gravenhurst, Orillia, Collingwood, Barrie and Penetanguishene in accessible, public locations such as Long-Term Care Homes, a Seniors’ Club, the NSM CCAC Office, a Native Friendship Centre and a Community Centre. Over 150 guests attended that included residents and clients, health service providers, caregivers and family members. A broad demographic of individuals was represented ranging from youth to seniors, including residents and health care professionals from NSM’s Aboriginal and Francophone communities.

The purpose of these sessions was to engage NSM LHIN residents and their caregivers or family members to share their recent experiences with local health care, to provide meaningful input and feedback that will be shared with all Councils and Committees of **Care Connections** and NSM LHIN Leadership and Board to guide and ground our work going forward.

Each session was approximately two hours long and began with a briefing about the NSM LHIN’s role and approach in improving the health system in North Simcoe Muskoka through our collaborative **Care Connections** initiative (<http://www.nsmlhin.on.ca/goalsandachievements/careconnections.aspx>) - our LHIN’s unique approach to executing the work outlined in our Integrated Health Service Plan (IHSP) 2013-16. The majority of time in each session was focused on conversations with residents and caregivers about their experiences with the NSM health care system, what worked well, and what would have made it better for them. Opportunities for continued sharing and conversation were offered to all participants via the NSM LHIN’s ongoing ‘Stories You Share’ initiative, a new Patient, Family, Caregiver Advisory Panel being established by the LHIN, ongoing participation at **Care Connections** Council and Committee tables, online opportunities through surveys and information on the NSM LHIN website <http://www.nsmlhin.on.ca/communityengagement/getinvolved.aspx> , and conversations with NSM LHIN Leadership or Board members.

Objectives for the Community Engagement Sessions included:

- Engaging residents, clients and their caregivers and/or family members in dialogue to hear about recent experiences with local health care, to gain their perspectives and insights into what is working and how we could enhance the experience going forward. This information will inform the work of the Board, Executive and staff of the NSM LHIN as well as all participants in **Care Connections** Committees and Councils.
- Educating the community on the role of the NSM LHIN, our **Care Connections** initiative and involvement of persons with lived experience in our work to date and in future.
- Seeking volunteers for the new NSM LHIN Patient/Family/Caregiver Advisory Panel and to participate in the ongoing work of **Care Connections** that will represent the community of North Simcoe Muskoka both geographically and by diversity.

Common Themes

There were many themes identified in these sessions that are consistent with what has been heard at previous engagements with clients, residents and professionals. Below is a summary of some of the key themes highlighted that will be explored in more detail in this report:

- **Transportation:** within the community (public transit, etc.), inter-community, costs
- **Navigation:** knowing what services are available, knowing how to access them, mapping the patient journey, resources (211 role and range of services need to be better known)
- **Customer Service Values:** patient perspective, treating patients/clients with respect and compassion, listening, partnering with patients and caregivers from the perspective of “nothing about me without me”
- **Access to Primary Care:** availability of doctors, limited or no doctors taking new patients, lack of 24/7 ambulatory care, after-hour care, walk in clinics
- **Community Supports:** in home and community care resourcing, wait times, availability
- **Caregiver Support:** caregiver health issues and burnout, what are we doing to support these people who are partners in keeping patients at home and out of the system
- **Wholistic Care/Prevention and Wellness:** what are we doing to keep people out of the health care system, talking to children/youth about living healthy, nutrition, social determinants of health (poverty + poor nutrition = candidate for health care)

Local Discussions

August 15, 2014: First Nations, Métis and Inuit (FNMI) Health Focus

After a quick information sharing portion about the role of the LHIN and how Health Links are working with local communities as described by Brenda Jackson, Aboriginal Health Link Coordinator, the large group of attendees broke into four smaller discussion groups.

In reporting back to the group at large, common themes included the suggestion that health care professionals be educated in and more open to cultural diversity – there is more than one way to be treated and assisted. By working together with practitioners and traditional healers, care would be much more wholistic, inclusive and culturally appropriate or sensitive. FNMI clients can feel intimidated when entering the medical system for treatment or leaving their community for services.

Participants see great opportunity in having Aboriginal navigators and community support that would work with local health care providers to assist FNMI clients through care transitions in the system and back into their homes and communities.

Patient navigators would provide an accessible ‘point of contact’ for clients, caregivers and health care professionals on a wide breadth of knowledge, from birth (e.g. doula and midwives) to end of life care, proper nutrition and wellness throughout life. This wholistic approach would be more reflective of Aboriginal beliefs, traditions and way of life.

In a geographically diverse region like North Simcoe Muskoka, transportation (cost, distance, accessibility) was flagged as a barrier to accessing services to some remote or more difficult to access communities like Christian Island, for example.

August 18, 2014: Muskoka

With a smaller group attending this session, discussions were held in a much more conversational format. Long-term care home (LTCH) staff and administration consider 'customer service' and treating their residents with care and dignity as one of the most important pieces of their work. As such, when they see patients or clients in other health care settings being treated in a lesser manner, it is very difficult not to intervene or report on the situation.

One clear challenge in the Muskoka region is access to medical services after hours. Those trying to avoid the ER by going to a walk-in clinic, face a 4-5 hour wait time before they are seen. Even patients who are attached to primary care physicians or have appointments get bumped and have long waits with so many walk-ins.

There are issues in transitioning from one provider or service to another, e.g. LTC to hospital or vice versa. There are gaps in service that need to be addressed by these organizations who need to work together to improve the flow of care for their patients and residents. Education for the public/clients and health care staff about best practices and available services would be useful in this case.

Some clients felt that based on the way they were dressed or looked when entering the emergency room that assumptions were made – they felt like they weren't treated with respect.

Positive things are happening as well. One client is having a very positive experience with The Pines, noting a great atmosphere of caring. The organization seems to have a great culture.

A board member of a local health care provider organization noted that boards are making tremendous strides in being community players and now is the time to have conversations about customer service and how providers can better serve our residents and clients.

August 19, 2014: Orillia and Area

Discussions began with a question about where seniors with little money or resources would go to seek assistance or advice. This sparked discussion about the services of Community Connections' 211. Although some residents attending this round of community engagement sessions are aware of or have used 211 to get information about local community and services available, this was new information for many and suggested that this be an advertising/education priority. This service would be very helpful as navigation was flagged as a barrier to finding available services.

There are clients and residents that fall through the cracks – perhaps they are unable to self-advocate or don't have friends or family to support them. This prompted discussion about clients with invisible symptoms or problems, e.g. mental health or addictions, or symptoms of stroke, heart attack, brain injury, etc. Patients who suffer from these symptoms or resulting conditions may have difficulty understanding or navigating the health care system. This can make patients feel even more vulnerable. Education for health care professionals was a suggested solution as well as educating those in the community like police, fire or other services who work with residents and health care providers.

It is often difficult for those who are caregivers to a loved one with health care issues to access support services – often services are only available at certain hours (e.g. 9am-5pm). What about weekends or after hours when support is needed or flexible weekday hours for those who work outside of the usual business hours?

Finding support in this area for a breast cancer or stroke survivor was difficult – one participant had to go to Barrie to meet with a group. It was difficult finding information following treatment – unfortunately she didn't know about 211.

The ability for doctors and other health care providers to be able to share electronic patient records was noted as extremely beneficial – clients no longer have to tell their story over and over and their records are current and complete as they move through the system.

August 21, 2014: Collingwood, Wasaga Beach and Area

Attendees of this engagement session were curious to know if residents from the Collingwood/Wasaga Beach area were participating in the work of *Care Connections* and the NSM LHIN and it was confirmed that they were.

Residents flagged that it is difficult getting care locally 'after hours', i.e. at a community clinic, knowing that they don't want to go to the hospital ER for things that aren't emergencies. Wasaga Beach and Stayner residents must go to Collingwood for after-hours assistance.

Several clients stated that being assisted by Personal Support Workers (PSWs) was key to their health and ability to manage, but were angry that PSWs themselves don't seem to be valued (i.e. not paid enough, not supported, consistency in providers or scheduling is problematic for clients and PSWs). There needs to be a shift in the way PSWs are valued. It is difficult to recruit them in the current competitive model, particularly with variances in wages.

Adding Nurse Practitioners or Physician Assistants to doctor's offices would allow local primary care practitioners to be able to see and assist more clients/residents who would receive the appropriate level of care.

Again, a more wholistic approach to health care – prevention and wellness – was flagged as a way to help reduce the overburdening of the system.

Although it was felt that we are moving in the right direction with 'baby steps', most want the system to shift faster towards true patient-centred care, to move into action and change now.

August 25, 2014: Barrie and Area

Clients and caregivers spoke about the different levels of service they have received at the various ERs and hospitals across North Simcoe Muskoka. The key to it being a positive experience was the way they were treated, the 'people skills' of the staff and volunteers who are a patient's first point of contact. Having had an experience with a heart attack already, one couple knew what they were experiencing the second time. Quick action is key to treatment and recovery, but the caregiver to the client felt that she wasn't heard by ER staff. They waited for hours until her husband did have a second heart attack. They had nothing but great things to say about experiences with paramedics and first responders (fire

department) and wished that instead of driving themselves to the hospital that day, they had called 911. But the question remains: why should that effect the service you receive?

Getting a family doctor in the area used to be very difficult, but is a much better process now with Community Health Centres and Family Health Teams. While health care providers at the session also mentioned the services of 211, nsmhealthline.ca and Health Care Connect in finding out what services are available in each community, it is evident that more efforts need to be made to raise awareness about these services.

It was noted that there is a lack of primary care available in Innisfil for those who have after-hours needs (as many of the residents do, being commuters who travel to and from Toronto for work). This is what causes the backup at ERs, as people have no other option. The system currently seems 'top-heavy' and unable to be nimble or responsive. The nurse practitioner clinic/model of care would be a welcome addition to the community.

Another patient recalled not having such a great experience in hospital (she had a bed in the hallway for three days and nights) and when finally given a room, the bathroom was unsanitary. She was grateful that a friend was able to come and help/advocate for her as she was weak with pneumonia and unable to advocate for herself. In such a fragile state, patients shouldn't have to fight for service or help. "When you're sick you cannot stand up for yourself, you can't make them change. And as a patient in the system, you don't want to upset the system while you're in it." She was able to compare this to some excellent past experiences in the health care system when she was treated respectfully and felt listened to.

Several attendees flagged that caregivers and volunteers are key groups of informal providers that need to be supported. Without these people, there would be no way to keep clients in their homes or get them back to their homes after treatment.

One suggestion was establishing a community volunteer 'pool' rather than only having volunteers attached to a particular organization. Some people may be more inclined to volunteer if it's a flexible system (less scheduled/regimented).

August 28, 2014: Midland/Penetanguishene and Area

While registration filled up quickly for this session, citizens who arrived without registering were invited to join in and share their stories about the local health system. LHIN staff were on hand to have conversations and provide information as well as materials in both French and English.

Apart from this session, NSM LHIN has been in conversations with and is in receipt of helpful input provided by the Midland Seniors' Council, who has had several meetings with local politicians and LHIN representatives about health system concerns.

A key concern of many of the attendees was the proposed closure of the Penetanguishene site of Georgian Bay General Hospital, and transfer of existing services to the hospital's Midland site (1.2 km away). Many were worried about increased travel time for services, or the lack of local services. For example, moving dialysis out of Penetanguishene would be a challenge for those with transportation issues already (increased costs can be prohibitive for some residents/clients). Lack of local lab services also contributes to travel and transportation challenges for many.

The closure of some palliative care beds in the region – the number of beds has decreased over the years while the population of seniors continues to grow – is also worrisome for many.

Finding and waiting for ophthalmological services meant that one client's health issues weren't identified and treated early enough to prevent loss of vision. Included in this caregiver and patient's concerns were navigation and transportation difficulties.

One attendee noted that having the new cancer treatment centre in Barrie at the Regional Health Centre was so helpful for him and his wife while she received treatments. Not having to drive to Toronto was a relief and so much easier. It was noted that when their journey started at Sunnybrook, the eHealth system of records was very advanced and helpful and is hopeful that this will become the norm in North Simcoe Muskoka as well. Allowing health care professionals to share health records and information electronically eases navigation burdens for clients and caregivers.

Access to specialists and consistency of service was a concern for many – doctors have so many patients, and little or no time to spend having dialogue/conversation. There is also an inconsistency in follow up services or treatments and payment/billing models between specialists which is confusing to clients and caregivers.

There are a number of other factors that add to the complexity of getting health care service in the Midland/Penetanguishene area: seasonal influx of residents, the growing population of seniors and retirees, the sheer size of the region, and remote communities that need to access services.

Conclusion

It is clear there needs to be more education – for all professionals with regard to cultural considerations and appropriateness, including the client as part of the decision making ‘team’ and old-fashioned ‘customer service’ skills, as well as for the public around helpful tools like calling 211 or visiting nsmhealthline.ca or Health Care Connect via the CCAC to access local information or primary care services.

Attendees were informed of the many ways they are able to get involved with or share their stories and ideas with providers and stakeholders in the local health care system, in addition to these engagement sessions.

There are currently many patients and caregivers who are members of the Councils and Committees of **Care Connections** (<http://www.nsmlhin.on.ca/goalsandachievements/careconnections.aspx>). NSM residents are always encouraged to contact the NSM LHIN Communications and Community Engagement team at any time for further information on how to get involved.

The NSM LHIN is also forming a Patient/Family/Caregiver Advisory Panel to provide advice, perspectives and suggestions regarding current work and future opportunities for changes and improvements.

Details and an application can be found at:

<http://www.nsmlhin.on.ca/communityengagement/getinvolved.aspx> or by contacting Sheila Winegarden, Community Engagement Coordinator at the NSM LHIN. Residents can also share their stories or ideas about local health care at any time via ‘Stories You Share’ which can be found on the LHIN website as well or by contacting the Community Engagement Coordinator.

Engagement with local residents and stakeholders within North Simcoe Muskoka will continue through various methods and we hope clients, caregivers and families will take the opportunity to share their stories and experiences to help improve the local health system for all.

This collection of experiences, feedback and insights into local health care across the North Simcoe Muskoka region is a valuable source of information that will be shared forward with the Councils, Committees and Working Groups of **Care Connections** (which includes a great many representatives from health care organizations and partners across the region and other key stakeholders), NSM LHIN staff and Board Governors.

The thoughts and experiences of our patients and their caregivers or family members will inform and focus the work being done to improve local health care to help ensure that our residents receive the right care in the right place at the right time.