Meeting Outcomes
from the

Share Care Council

March 1, 2014

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TABLE OF CONTENTS

ACKNOWLEDGEMENTS

Thank you to participants for their tremendous insights and commitment to helping people in our community.

From Mississauga Halton CCAC

Rob Stansfield, Board Chair, Mississauga Halton CCAC (for introduction)

David Fry, Vice President, Client Services, Mississauga Halton CCAC (for introduction)

Nancy Gale, Director, Strategic Communications and Stakeholder Management, Mississauga Halton CCAC

Kathryn Hales, Executive Assistant, Mississauga Halton CCAC

Marian Pitters, Facilitator, Pitters Associates

Karen Metcalfe, Senior Consultant, Pitters Associates

EXECUTIVE SUMMARY

The Mississauga Halton CCAC invited fifteen patients and/or care givers to attend the inaugural ***Share Care Council*** meeting on Saturday March 1, 2014. The purpose of the ***Share Care Council*** is to engage and partner with patients and families from across the region to provide feedback to inform new programming and services and to identify areas of priority from the perspective of community-based health care. This purpose supports the second area of focus of the Mississauga Halton CCAC's 2011-14 Strategic Plan: Client & Family Focus.[1]

To open the session, the Board Chair and the Vice-resident Client Services welcomed everyone and thanked the members for making a significant contribution by volunteering their time to this very important initiative. They acknowledged the impact of the inclement weather and changing health circumstances on invitees' attendance, and expressed their appreciation to the seven individuals that attended.

An overview was provided of the major trends that are impacting community care and how members' insights would help the Mississauga Halton CCAC address those trends. They assured the members that their ideas and suggestions would be considered carefully and would help inform the development of Mississauga Halton CCAC programming and services that are better for all patients and their families.

Following those opening remarks, members introduced themselves and described their hopes for the ***Share Care Council*** as patients or caregivers. A ***Share Care Council*** Terms of Reference was reviewed and revised and will be updated annually. Members then discussed guidelines for how they wanted to work together in ***Share Care Council*** meetings. They confirmed the importance of their confidentiality agreements to members' privacy with: "*what gets discussed in the room stays in the room".*

A list of six potential discussion topics that would inform current programming were presented, and clarified, including:

1. Caregiver relief
2. Your care with your family doctor
3. Your experience moving from hospital to home
4. Getting health and wellness educational resources
5. Taking control of your own health – health planning for longer-term care and end-of-life
6. Sharing your health record with your circle of care

Additionally, members were invited to identify two topics; they identified three and they ranked all topics, identifying these topics their top choices for discussion:

- What is my caregiver's job (PSW, supervisor) and family member's job?
- Quality control experience
- Choice of agency service provider

Members then discussed how the priorities would be dynamic and might change as the Mississauga Halton CCAC representatives updated them on upcoming opportunities within the system. When the Director, Strategic Communications and Stakeholder Management informed

[1] See http://healthcareathome.ca/mh/en/Documents/MHStratPlan1114.pdf p. 4

members of an opportunity related to the topic "*your experience moving from hospital to home*", the members decided to focus on this topic first. Their experience-based suggestions focused on a number of initiatives that would set people up at home so they could function with confidence, effective resources and support to prevent re-admission. As one member summarized: "*We shouldn't have to fight through the system - what we are asking doesn't cost the CCAC more. Assume the norm is quality care, done right the first time."*

This report summarizes the discussion highlights of this inaugural ***Share Care Council*** meeting, the details of which are appended. The feedback summary indicates that members appreciated each other's willingness and comfort to share ideas as well as to listen. They are eager to continue these discussions with additional Council members at their next meeting in June 2014.

OPENING REMARKS

Rob Stansfield - Board Chair, Mississauga Halton CCAC

Rob Stansfield welcomed everyone to the inaugural meeting of the ***Share Care Council***. Here is a summary of his opening remarks.

- You are making a significant contribution by volunteering your time to this initiative. Your commitment to help us out is really appreciated.
- The broadest definition of volunteerism is doing more than you have to because you want to and because you consider it good. We think the ***Share Care Council*** is very good.
- Your ideas and suggestions will help us develop programs that are better for all of our patients and their families.
- One of you said that this is your responsibility and we appreciate that sentiment.
- Health care is something that impacts all of us and remains one of the top priorities for most Canadians. For us, it's not about policies or politics: for us healthcare is about our day to day lives and those of our loved ones, e.g.,
    - *"My mother is leaving hospital and I don't know how to provide her care at home"*
    - *"How are we going to cope as my husband gets worse"*
- With very tight resources we must design our services to provide the best care to the largest number of people in our community.
- I want to share with you some information about our Community Care Access Centre and the patients we support. I think it will help you see who you are representing.
- First of all, the Mississauga Halton CCAC serves the communities of South Etobicoke, Mississauga, Oakville, Milton and Halton Hills.
- Last year, we cared for 41,172 patients. And those patients received almost two and a half million care visits.
- We care for more patients with complex care needs than ever before. Those patients used to be in hospital – now they are cared for at home by us.
- And this is just going to increase. The population in our region is expected to grow 46 per cent over the next 15 years. The number of people 75 years and older will increase 143 per cent by the year 2030.
- Plus, over past four years, emergency department visits in our region's hospitals was double the number of visits in the rest of Ontario.
- We hope you can help us come up with ideas today. We can't do everything but we hope this will be a good start.
- This Council is near and dear to the Board. We see you giving us advice, telling us what's working and not, being a sounding board. We do need you to be open, candid and frank. Tell us what you think we need to hear. We are always going to be open to hearing your suggestions and ideas.
- We want you to take the conversation where it needs to go.
- If you ever feel you need to speak to the Board, our doors are always open.
- "*To the world you may be one person, but to one person you are the world."*

David Fry - Vice President, Mississauga Halton CCAC

David followed up on Rob's opening remarks, as follows.

- I am glad to see this meeting happening. I see you as being able to help us improve services, put our money where our mouth is. We talk about patient centeredness but this is one of the ways we want to actually do that.
- It is about shared care between us, you, hospitals, and health care professionals.
- *David then told a personal story about his belief in shared care*. When I first started working in home care as an occupational therapist, I had an awful lot to learn. I knew a lot from best practices. I thought I was doing my best by listening to a patient who had a stroke and problems with topographical orientation. So every morning when he got up, his house seemed to him to have a new layout - he didn't remember from the previous day. His wife was getting frustrated and we sat and had a frank conversation. I expressed some of my frustration with not being able to help. And she said, *"You listen to us every week, you respected what we said."* We truly had shared care. We brought our knowledge together and were working together.
- For this Council, that is what I want us to do. We will listen and be open to your ideas, using suggestions when and where we can. We really are going to listen to your perspectives on where we should concentrate our energy.
- Thank you; we truly appreciate your commitment.

HOPES FOR THE SHARE CARE COUNCIL

*Participants introduced themselves and shared with the group their hopes for the **Share Care Council.** These were their responses:*

- Improved communications (3)
  - To make communication of our needs easier, e.g., just to get someone to get me here today, it took a lot of coordination and some confusion to sort it out
  - Communication needs to be better coordinated
  - Solve some communication problems
- Help to streamline the CCAC's focus – there is too much wasted usage of CCAC
- To bring forth the voice of my daughter, she's a minority in a minority group - 25 years old and in the system since she was a baby
- To find a place to make positive comments about the CCAC. There seems to be a negative view of the CCAC in general because they refuse a lot of services but there is a lack of understanding of what the CCAC does. There is no spot on the website where you can make positive comments. We are too focused on the negative.
- Extra hours in caregiving

GUIDELINES FOR DISCUSSION

*Participants discussed what they learned in grade school that they hoped people would follow when working together today. Building on these ideas, they decided on the following as guidelines for discussion within the **Share Care Council**. A copy will be included on tables at the beginning of each meeting with a verbal reminder of the guidelines.*

a) Build an atmosphere of acceptance so everyone feels that they can speak up with no fear of service removal.
b) Let other people speak, listen.
c) Build on what others have to say.
d) Be polite, e.g., let people finish their thought, don't interrupt.
e) Allow everyone to complete their thoughts.
f) Address one another by name.
g) Be encouraging, e.g., develop a culture where people feel they can express themselves and not be judged.
h) Make sure everyone is clear before moving to the next topic, e.g., paraphrase to everyone's satisfaction and ensure ideas are captured accurately.

COMMUNITY CARE PRIORITIES

Share Care Council members were presented with a draft list of priorities for new programming and were invited to add to the list. Following clarifications, members rated the topics (see Appendix), the top three of which were:

- **What is my caregiver's job (PSW, supervisor) and family member's job?**
- **Quality control experience**
- **Choice of agency service provider**.

Members then discussed how the priorities would be dynamic and might change as Mississauga Halton CCAC representatives updated them on upcoming opportunities within the system: "*We are here for the greater good."* The Director, Strategic Communications and Stakeholder Management informed members of an opportunity related to the priority "*your experience moving from hospital to home."* Senior leaders of health care organizations were looking for patient/caregiver input on this topic in preparation for a with CCAC and hospital executives next week. The members decided to focus on this topic first. Their contributions and suggestions follow.

Topic #1: Your Experience Moving from Hospital to Home

Dreams - what would be different for patients and caregivers in three years' time?

- Need to know that you're not alone
- Family conference before discharge increases confidence (you do not get discharged until this happens):
  - Should include entire team – OT, family doctor, nurse, PSW, case manager, etc. Include anyone who is going to be at the home (healthcare workers and family)
  - Explain how the system works so you can work together to have quality care
- A personalized map, plan and/or package provided before leaving the hospital, including:
  - Transition plan in writing that can be shared with family and caregivers. Verbal plans are not remembered.
  - What to expect in the first few weeks after returning home
  - Names and phone numbers that will work 24/7, e.g., you are going home, at 7 pm Mr. Smith is going to be at your house, if he's not, this is who you call; what to do when no one shows. Ensure health care professionals are not overbooked.
  - List of medications and what they are for, possible side effects
  - Anticipate current and future needs – what people can expect
  - Who to call and what to do if something happens
- Set up families to be successful at home so they can prevent re-admission:
  - People are often stable when discharged but still very complex - too much responsibility is put on caregivers.
  - Hospitals need to know what they are discharging patients to
  - Ensure that people and equipment are in place before discharge
  - Consider family/caregivers' work situation
  - Caregivers need to ask: "can you explain what that is?"
  - Need a person that is not rushed, that will spend time with people, e.g., they explain what is going to happen, train in equipment being used, make sure you are

comfortable, provide contact information with assurance that they can be called any time for any reason

- Access to healthcare professionals in the home when needed
  - Consider videoconference, mobile webcams for consultations; remote vitals. Check out technology from Thunder Bay and Sick kids. Care coordinator could facilitate this. Video doctor visit (VDV)
  - Don't say "see your family doctor in a week" - need an alternate doctor to access, make decisions. Doctor who comes to the house is the best
- Need a dialogue that can include everyone no matter condition or age, e.g., seniors with dementia – speak to them at their level
- Connect systems so family doctors are updated ASAP – whose role is this?
- Shouldn't have to fight through the system; what we are asking doesn't cost CCAC more. Assume the norm is quality care, done right the first time
- Include objectives and measurements, holistic view and assessment

NEXT STEPS

Participants discussed what steps need to be taken after the day.

1. **Finalize the meeting outcomes report:**
   - March 8 - Draft report completed by Pitters Associates
   - Distribute report for review by participants to make sure it captures what was intended
   - Finalize reports and share with Mississauga Halton CCAC Board of Directors, CCAC and hospital executives involved in new programming, ***Share Care Council*** members that could not attend and other stakeholders

2. **Prepare for next Share Care Council meeting in June 2014:**
   - When: Saturdays from 10:00am-2:00pm (be mindful of people's work schedules) – to be confirmed by CCAC staff
   - Meeting type: Face-to-face
   - Where: Homewood Suites, Oakville
   - Agenda: Check in on progress

APPENDIX: AGENDA

DATE: Saturday, March 1, 2014
TIME: 9:30am – 2:00pm
LOCATION: Homewood Suites,
2095 Winston Park Drive
Oakville ON L6H 6P5
OUTCOMES:
- Review the purpose and guidelines of the Share Care Council
- Provide input on priority topics
- Determine next steps

Item	Agenda Item Description	Time	Lead
	Breakfast	9:30 am – 10:00 am	
1.0	Opening remarks	10:00 am – 10:10 am	Rob Stansfield, Board Chair
2.0	Development of Share Care Council	10:10 am – 10:20 am	Nancy Gale, Director Communications
3.0	Overview of agenda • Introductions, including hopes you have for Share Care Council meetings • Guidelines and tools for how we will work together	10:20 am – 11:10 am	Marian Pitters, Facilitator
4.0	Community Care priorities • Discussion: what topics are most important to your health care experience?	11:10 am – 12:00 pm	All
	Lunch	12:00 pm – 12:30 pm	
5.0	Community Care Topic • Discussion: what would the ideal experience look like/feel like?	12:30 pm – 1:50 pm	Marian Pitters
6.0	Next steps and meeting evaluation	1:50 pm – 2:00 pm	Marian Pitters
7.0	Adjourn meeting	2:00 pm	All

APPENDIX: TERMS OF REFERENCE

SHARE CARE COUNCIL

TERMS OF REFERENCE
(Revised March 1, 2014)

BACKGROUND

The Share Care Council (SCC) includes individuals (including patients and family caregivers) representing the patient populations in the Mississauga Halton CCAC (MH CCAC) region, as well as MH CCAC staff representatives. A strategic pledge central to this forum (2011-2014) is that clients and families have a direct voice in our programs and services, as part of our vision to provide "outstanding care - every person, every day."

PURPOSE

The purpose of the SCC is to engage and partner with patients and families from across the region to provide feedback and to identify areas of priority from the perspective of community based health care.

SCOPE

The scope of the SCC is to share ideas based on patient/family member experience to:

- Develop a collective vision of patient centred care and improving the patient experience.
- Generate areas of focus and priorities.
- Advise on strategies for actively partnering with patients in designing, planning and improving health care services (such as experience-based co-design).
- Review evaluation methods to help define success of system improvements.

ACCOUNTABILITIES OF MEMBERS

- Collaborate on agenda items and priority areas of work for SCC
- Regularly attend and be an active participant in council meetings and important related meetings, prepare for meetings and, review and comment on minutes and reports.
- Members may be invited to participate on other MH CCAC sub-committees and offer advice on other MH CCAC initiatives.
- Submit expected travel expenses within one month of SCC meetings.
- Sign a non-disclosure and conflict of interest agreement.

MEMBERSHIP

- Patient and Family member representatives from client populations (approximately 16 - 18).
- Selected MH CCAC staff members.
- Meetings will be Chaired by the Vice President, Client Services or the Director, Strategic Communications and Stakeholder Management

TERM

- The term is a two year membership with the possibility of a one term renewal.
- Members may withdraw from membership at any time and by any means (i.e. written or verbal).
- In the management of term renewals, consideration will be made to maintain a balance of new and experienced members.
- Terms of Reference/ Membership to be reviewed annually

MEETINGS

- Four meetings annually (two conducted in-person and two conducted via videoconference)
- The agenda, previous minutes and related materials will be provided by MH CCAC administrative support at least one week prior to the meeting date.
- Members may be asked to review and comment on relevant documents circulated electronically between meetings or through ad hoc meetings.
- Recommendations will be made by consensus of the members present at the meeting. If the meeting is attended by 50% of the membership, decisions hold.

APPENDIX: RATING OF TOPIC IMPORTANCE TO THE HEALTH CARE EXPERIENCE

Members rated the topics that were most important to improving their health care experience on a scale of 1 to 8: 8=very important, 4=somewhat important, 1=not important.

Topic	Avg	Each Participants' Rating						
		1	2	3	4	5	6	7
What is my caregiver's job (PSW, supervisor) and family member's job? • Moving people with different abilities and in different situations • Training people • When does the caregiver get a break? • Family members shouldn't be in the room when care is there • No consistency in the type of worker you get • Caregiver and patient situations	**6.7**	8	4	8	4	8	7	8
Quality control experience (relief), e.g., • Checks and balances with PSW agency • Delivery and efficiency	**6.6**	6	5	4	8	8	7	8
Choice of agency service provider: • Who makes the decision and communicates it? • What say do we have? You feel like just a number • What can we say when speaking up?	**6.3**	8	3	8	2	8	7	8
Navigating the system, e.g., on a day to day basis who do you call to bring up issues (big or small)	**5.8**	4	8	4	1	8	8	8
Caregiver Relief	**5.7**	8	6	6	2	5	6	7
Your care with your family doctor	**5.6**	6	5	6	3	6	6	7
Your experience moving from hospital to home	**4.6**	6	4	4	3	7	8	--
Getting health and wellness educational resources	**4.3**	7	2	8	2	4	7	--
Taking control of your own health, e.g., health planning for long-term-care and end of life)	**4.1**	6	7	4	1	4	7	--
Sharing your health record with your circle of care (doctors, nurses, pharmacists, care coordinators and others)	**3.8**	8	3	4	1	4	7	--

APPENDIX: SUMMARY OF SESSION FEEDBACK

All seven participants completed the evaluations. Numbers in brackets, e.g., (4), indicate the number of times a similar response was noted. Responses to the same question may represent different points of view.

1. The extent to which participants thought the outcomes of the session were successful:

	1 Poor	2	3	4	5 Excellent	Average
Review the purpose and guidelines of the Share Care Council	0	0	0	0	7	**5.0**
Provide input on priority topics	0	0	0	1	6	**4.8**
Determine next steps	0	0	0	0	7	**5.0**

2. What participants found most useful about the session:

- Willingness and comfort to share ideas that are listened to (6), e.g.,
  - Good communication of ideas
  - We can provide insight and input into future decisions/strategies as an individual and group
  - That what we say people are listening
  - People are open
  - Many ideas put forward, much more informed
  - How much input everyone was willing to give
- CCAC participation, Board Chair and senior leadership attendance
- Scope, guidelines and approach

3. Words of advice for future Share Care Council sessions:

- Continue this good work, keep doing what you are doing, keep it up! (6)
- Proof is in the pudding. Keep promises and update

4. What participants wanted to say but didn't:

- Nothing
- That is never a problem, I got to say it all
- All well covered

5. Other comments:

- Best regards
- It was affirming to hear others' experiences and challenges. We are not alone.
- Great idea
- Very good presentation. Enjoyed the day immensely – thank you.
- Thank you for this opportunity.
- Great venue, good organization and facilities, good facilitator.