



Mississauga
Halton
CCAC **CASC**
Community
Care Access
Centre
Centre d'accès
aux soins
communautaires
de Mississauga
Halton

Meeting Outcomes from the

Share Care Council

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March 4, 2017



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ACKNOWLEDGEMENTS

“On behalf of the 1.2 million residents in our region, thank you very much.”

Thank you to all participants for their dedication, willingness to share their experiences for the greater good and constructive guidance provided to the Mississauga Halton CCAC.

Nancy Gale, Associate Vice President, Strategic Communications and Partnership Advancement, Mississauga Halton CCAC, Co-lead, Share Care Council

Kathryn Hales, Patient Relations Associate, Mississauga Halton CCAC, Co-lead, Share Care Council

Marian Pitters, Facilitator, Pitters Associates

Karen Metcalfe, Senior Consultant, Pitters Associates



EXECUTIVE SUMMARY

On Saturday March 4, 2017 the Mississauga Halton CCAC hosted its eleventh and final meeting of the inaugural Share Care Council (SCC) . The purpose of the SCC is to engage and partner with patients and families from across the region to provide feedback and recommendations to inform the development of new programs and services. This purpose supports the first strategic direction of the CCAC`s strategic plan for 2015 – 2020: Meaningful Experiences & Outcomes.¹

To open the session, Marian Pitters, the facilitator, welcomed the SCC members, acknowledging that the day would focus on transitions. “Transitions can be difficult, and feel like Linus without his blanket. But you have to deal with endings first before you can have a new beginning. We’ll help each other with this today.”

Marian continued by providing an overview of the agenda (see Appendix A), highlighting the excitement of being part of such a momentous occasion. Participants reflected on their experiences as members of SCC, among which four main themes emerged (details that support the themes can be found in the next section):

- We had rich discussions where everyone shared openly and respectfully.
- There was always a positive feeling of support as everyone was treated with empathy and compassion.
- We were working towards a common goal, achieving results and doing something good. It needs to continue.
- The leadership, facilitation and process set us up for success.

Following the discussion, Nancy Gale, Associate Vice President Strategic Communications and Partnership Advancement, provided an update on the CCAC transition to the LHIN:

- Work continues with the MH LHIN Board to dissolve the MH CCAC Board
- One SCC member came to a MH LHIN Board meeting on July 13, 2016 and shared her personal story of caregiving for her husband, listing the progress that SCC has informed were impactful to the LHIN Board and attendees.
- The date of transition for *Patients First* is still unknown; however, April 7th is the target date when the Minister will sign transfer documents to inform the exact date of the transition order
- Everyone has been working on the readiness for change and we are prepared for the transition.

Nancy reassured members that although the SCC will fall under a new organization and new teams, the information from today’s discussion and report will be shared with the Mississauga Halton CCAC executive team, the MH CCAC Board of Directors and with the MH LHIN

¹ See

<http://healthcareathome.ca/mh/en/care/patient/Documents/MH%20CCAC%20Strategic%20Plan%20Booklet%20Final.pdf> p. 4

executive team, including the organizational impact report which captures beautifully the achievements and the impact Share Care Council has had.

Kathryn Hales, Patient Relations Associate, Mississauga Halton CCAC, distributed the organizational impact report to the SCC members and provided an overview of how each page featured a different project to which SCC contributed. The reports will be shared with members of the management team and Boards to highlight the many contributions of the inaugural SCC.

In conclusion, Kathryn listed the stakeholders that received information on the important work and contributions of SCC since its inception:

- 14 Service Provider Organizations
- 530 staff
- MH CCAC Board of Directors
- MH LHIN Board of Directors
- Health Quality Ontario
- Ontario Association of CCACs (OACCAC)
- Association of Family Health Teams of Ontario
- Provincial Patient Ombudsman
- National Forum on Patient Engagement
- Community Quality Network
- Local Members of Provincial Parliament
- Ontario Gerontology Association

“I hope you all feel satisfied and proud of your work. Thank you for all you have done.”

This report summarizes the meeting highlights, a review of the SCC experience, reflections, an assessment of the meeting structure, terms of reference, guidelines for discussion and membership, as well as recommendations for the next SCC; we hear final words from each member. Most participants showed a mixture of feelings at the end of the meeting, knowing that they were going to miss being a part of the Council. Perhaps the strongest feelings in the room included pride for what had been accomplished, appreciation for the opportunity to participate, and gratitude for the friendships that had been forged. Many nodded in agreement when one member said:

“I think this is a great opportunity to pay it forward and it’s important that we advocate for those who need it. Meeting all of you was wonderful”.

HIGHLIGHTS OF THE SHARE CARE COUNCIL EXPERIENCE

When asked about one thing that they wanted to make sure was highlighted about their Council experience, SCC members had a difficult time limiting their comments to “one thing”.

- **There were rich discussions where everyone shared openly and respectfully**

“Diversity of experiences was a strength. It hit on every level of care and enriched discussions.”

“We may have disagreed but we felt free to say whatever we want – we had open and friendly discussions and that’s been the fun of being a part of this group.”

“We accepted the journeys that people have been on and used that to move our discussions forward. We had a maturity and an understanding. Our situations were different and everyone had a contribution that is eye opening to the rest of us.”

“You don’t feel like you have to always speak, because others say it – you are part of the group and are heard even if you are quiet.”

“I want to thank everyone for sharing difficult stories, people haven’t held back. Thanks for sharing your lives.”

- **There was always a positive feeling of support as everyone was treated with empathy and compassion**

“We haven’t been judgmental of each other; we’ve been a support.”

“At times we’ve shared very personal issues and people showed great compassion - that’s an amazing thing.”

- **We were working towards a common goal, achieving results and doing something good. It needs to continue.**

- **The leadership, facilitation and process set us up for success**

“Positive sponsorship from Nancy and Kathryn was essential – the chemistry worked. The humanistic approach they took with all of us brings the best out of people. “

“Facilitation was key. Marian, you gave everyone a turn and are a big part of why this worked. You cut people off when they needed to be and brought others into the discussion. I’ve been in groups where someone takes over and no one has a chance to speak; it is stressful and that’s not the case here. You’ve made sure everyone had a voice.”

“Facilities – never leave ‘The Homewood Suites!’“

REFLECTIONS ON SHARE CARE COUNCIL ORGANIZATIONAL IMPACT REPORT

Kathryn Hales distributed the organizational impact report and provided an overview of each project to which the SCC had contributed. The reports will be available on the website and it was suggested that they also be shared when future engagement activities are developed. Participants indicated they were pleased with how the booklet summarized their work and how their words could be found in the pages:

“The quotes really bring our experience to life.”

“Thank you, it looks amazing”

“We don’t get that perspective every time and this is a great summary of our work”

“Seamless transition really got me going. It really pumped me up and made me feel like we were doing something. It was right after my dad had a terrible transition and the meeting happened at a time when it was so raw. I’m so proud that we could help fix a huge problem for people. We can see ourselves in the document.”

There were different views on making the SCC member’s names public. Some would like to see a list of names, *“because this is a good group and I want us to be remembered. I think we deserve credit for it.”* Others wanted to remain anonymous. As originally discussed at the initiation of SCC, it was decided that it will remain up to each individual to say ‘I was a part of that’ but will not reveal the names of other members as per the confidentiality agreement

Participants also wanted to acknowledge the critical role of the Mississauga Halton CCAC:

“Thank you to Nancy and Kathryn. You brought real issues to the table for us to tackle.”

“We had ears on the other side listening about what changes were needed, from our perspective.”

“It is important that people at the heart of the organization (Nancy and Kathryn, Caroline and David) are here. People who are connected to operations ensure the message doesn’t get washed out and lose meaning. Operational and managerial accountability is needed for SCC to be successful.”

REVIEW OF MH CCAC SHARE CARE COUNCIL

All members completed an assessment of SCC according to five areas:

1. Meeting structure
2. Terms of reference
3. Guidelines for discussion
4. Membership
5. Other

Questions about the five areas invited both quantitative and qualitative responses. Following their individual reflection, members shared their responses with the group and engaged in a fulsome discussion. Members’ individual responses and group discussion highlights are captured below.

Meeting Structure

The structure of the Share Care Council meetings included introductory remarks from senior leaders and Board members, updates from previous meetings, two topics for discussion, and next steps. SCC members rated the extent that the meeting structure achieved the following:

Meeting Structure	1 Poor	2	3	4	5 Excellent	Average
a) clarified the meeting purpose	0	0	0	1	9	4.9
b) enabled participation	0	0	0	0	10	5.0

Reasons for the rating – a) clarified the meeting purpose:

- **Reports of the meetings were accurate and this built trust**

“Took comfort in knowing nothing was missed”

“It allowed us to have trust in the process. We couldn’t see what was being recorded. Audio recording was explained and we saw it in the minutes accurately so we were comfortable. The new Council will have their minds blown when they see this process. Nothing got missed that was important.”

- **Updates allowed us to see our impact, value**

“At first you wonder if the CCAC wants to say that we have a SCC and our discussions are meaningless. The updates showed us that we are not here in name only. It has a big impact and helps reassure us. Great to see how it is being used in the real world.”

“It encouraged more participation because it showed the value of being honest. Improvements were made and communicating those to us was important. Improvements were made so we didn’t just focus on identifying problems but looking for solutions. They

showed tangible changes, showed value and helped people change from whining and what doesn't work, to see how we can change the problem."

- **The facilitation and process worked - it kept us focused**

"When the pre-distributed agenda came, it allowed us to think ahead"

"When reviewing the agenda at the beginning, you ask if anyone has questions and feedback so everyone understands"

"This model has proven to work, why throw it out?"

"Change is taking place but there needs to be continuity. From either members, facilitator, staff, etc. There needs to be something."

"Most of the time was spent on what was important - a lot of time for discussions."

"Launch it using the same structure and people (Marian, Nancy and Kathryn). You need the strong foundation. If Marian wasn't the facilitator, it wouldn't work."

"Facilitator was the one person that kept control and made sure the agenda was adhered to and gave everyone the change to speak. That's why it worked."

"Ability to give feedback on the reports; let us give it a second consideration."

Reasons for the rating – b) enabled participation:

- **The facilitator was critical to encouraging and ensuring participation by all**

"Facilitator asked the right questions and was open to being challenged – openness encouraged participation."

"I would like to put a motion on the floor. If there is a performance clause, we as SCC vote that Marian's facilitation be honoured. [Unanimous vote] Good experiences should be noted."

"When we didn't have enough time to discuss a topic, it got brought to the next agenda. I was happy to see that because it was important to me. There is flexibility to correct when needed."

"Seeing the points noted on the flip chart was important, going back to it, asking for additions. It makes perfect sense (wasn't sure about this at first)."

Terms of Reference

When asked about the extent to which the Terms of Reference clarified their role and responsibilities, members of Share Care Council agreed that the document provided a foundation on which to build.

1 Poor	2	3	4	5 Excellent	Average
0	0	0	2	8	4.8

Reasons for the ratings:

With ratings at good or excellent, a few editing suggestions are highlighted in Appendix B. The discussion focused on how the “management of Term renewals” would be implemented in the future. In particular, members discussed two possibilities regarding “a balance of new and experienced members”:

- a) Everyone starts together and ends together with no overlap in their terms; or,
- b) Members serve for two years with rotating start dates and overlap so there are some old members and some new.

Perspectives on both options were discussed:

“I think there is a value in the new chemistry. Let them grow and be more cohesive. Plant the seed and let them grow.”

“[To have some existing members at the table], provides some continuity as there is always wisdom from ‘grandad’ at the table.”

“Too many of us experienced members would be intimidating [for the new members].”

“I think having a couple of our members give a presentation to the new group is a better approach. The group will have the opportunity to develop together and still get our information through the presentation with a Q&A.”

Guidelines for Discussion

Everyone agreed that the Guidelines for Discussion (and their review at the beginning of each meeting) helped to facilitate Share Care Council members’ constructive participation. The Guidelines are found in Appendix C.

1 Poor	2	3	4	5 Excellent	Average
0	0	0	1	9	4.9

Reasons why members chose that number:

“We made up the Guidelines. The next group should come up with their own. It gives them ownership.”

- **They are fair, clear and enforced**

“Started meetings with “respectful” and people need to hear it.”

“They are always enforced respectfully without heavy handedness or abrasion. It let people know they were going to have a turn.”

- **Helpful for new members**

“I joined later and it helped me interpret the engagement style. As a vocal participant, it let me know what to expect.”

Membership

In the past, SCC members were invited to participate in order to be representative of patient and caregivers populations. Participants brainstormed other characteristics that they thought would be most valuable when considering members for future SCC and/or patient engagement forums:

1. Have a greater age spread
2. Consider if other stakeholders, including non-family caregivers, would provide a useful perspective. Varied opinions evolved, including:
 - Non-family caregiver, e.g., retired PSW, retired nurse can provide an outside perspective
 - Expanding the membership list could lead to conflict of interest issues
 - People with disabilities need to be the focus
 - Adding other stakeholders dilutes the patient voice.

“We discuss with no limits, we imagine anything. There are no union issues, no closed doors.”

Key Elements for the “New” SCC First Meeting

Participants were asked to highlight key elements to include in a first meeting of the next SCC²:

- **Build on what we have learned, don’t reinvent what has proven to work**
 - Begin with a structured agenda
 - Give everyone an opportunity to get to know each other and share their stories (include name tags)
 - Keep the facilitator to help set the stage, provide expertise and bring in previous learnings
 - Invite Board members to make introductory remarks before meetings

² *“I wish they wouldn’t use SCC name because there won’t be another one like us, consider ‘LHIN care council’”*

“We’ve all been involved with organizations but how often do you have Board members on a Saturday morning come and share – they said personal things. You never see that. It showed us how invested they were and how important we were.”

- Continue to include ‘this is what you said, this is what we did’ into each meeting

“That’s how we knew our work was valued and validated”

- Continue to include breakfast

“It lets us get to know each other and talk casually, outside SCC responsibilities.”

- **Explain the confidentiality agreement more clearly and define parameters with examples**, e.g., what can you say when talking to people outside SCC? What can you not reveal?
- **Provide a list of projects and ask them to prioritize (as was done at the beginning)**, e.g., be clear about what we have already accomplished

“Keeping the same facilitator to help prioritize would ensure there was a link between our work and the new group.”

- **Be clear that the new SCC is here for the greater good not personal service perks, but that they will benefit as individuals**

“It helps me; it gives me purpose for the pain.”

“There are no kick-backs. It is not about your personal situation, it is about the greater good.”

“I get a lot personally out of being here. I think people you invite are going to be in the same position. An opportunity to pay it forward, give thanks. We’re grateful for what has been provided. It is a two way street.”

- **Address members’ fears that participation may have a negative impact on service by:**
 - Providing the information on where to go if they do have issues with their own service
 - Ensuring consistent people are in the room. This helped with trust and fear
 - Building trust through demonstrated results.

“We are asked to give very personal stories. Over time you don’t fear because you know you are being listened to, they implement, and then they share back to Council – the whole process was key. This is a unique way of doing this. I’ve never seen this before. The new Council is not going to believe it.”

- Sharing our experience, in our words

“After three years, no one here has been affected at all in their care (because of membership in SCC) and we were very open and honest about the problems, often brutally so.”

“If you are fearful about your service being impacted, there is no evidence from the past three years to support that fear.”

CELEBRATION AND FINAL WORDS

In the final component of the agenda, Nancy Gale and Kathryn Hales expressed their gratitude for each member of SCC.

“On behalf of the 1.2 million residents in our region, thank you very much.”

Each individual was presented with a framed certificate and a folio, accompanied by great rounds of applause. A surprise presentation of flowers was made to Nancy Gale, Kathryn Hales, Marian Pitters and Karen Metcalfe.

The celebration concluded with final thoughts from each of the SCC members. They all focused on words of thanks and appreciation for being invited to the SCC:

“I was happy to be part of this because I met a lot of wonderful, strong people”

“A nice group and it was a good time of cooperation and information. I got so much. Some of us have more information to give but the group worked together. I appreciated very much the work of the CCAC which really had to show us that we can do something. Sometimes when we get on in age, we don't know how much one can do. I try to use my time so that I can feel that I am not already finished, that I still have value. I come out of these meetings feeling like I am living and I can contribute. You young people may not feel it as much. I am 92. To feel that I have done good - I thank god for it. And it is good to get information and friendship. I appreciate very much what I got. I wish you the best with the next group and that they can start where we ended, not end where we started. Hopefully this will help our country because everyone is needed.”

“Thank you to Marian, you were marvelous. Good health to everyone.”

“I was totally flabbergasted. I didn't know what kind of group I was coming in to and how they found me. I sent an email about the terrific treatment I received and I got a call about participating in a video and the next thing I knew I was here. I've enjoyed it. Thank you for allowing me to be part of it.”

“This has been an incredible experience, part of the legacy for my son. I thank all of you for the support, amazing input you gave and it just seems so bright for the future.”

“This was my first real volunteer experience. We all have stories, my father passed through my hands in India and then our son passed away in 2010 and my mother passed away last year. We all have situations in our life and this gave me the opportunity to give something back, to make it better for others. Sometimes I speak too much. It's a wonderful initiative. Thank you all.”

“I think this is a great opportunity to pay it forward and it’s important that we advocate for those who need it. Meeting all of you was wonderful.”

“You all met me as I was coming out of a complicated and exhausting treatment program and this helped me contribute back to the angels that brought me back. I look forward to this every time – it gives me support and friendship. You have been my family. It’s made a big difference to my recovery and me personally. Thanks for letting me be here and for putting up with my overt discussion. I’m going to miss being a part of this.”

“I’ve been proud to be part of this. My husband said after the first meeting that I had a sparkle in my eye.”

“Thank you all in joining in the journey. We’ve all appreciated it. It’s been great.”

NEXT STEPS

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

1. Finalize the meeting outcomes report:

- Draft report completed by Pitters Associates
- Distribute report for review by participants to make sure it captures what was intended
- Finalize the report and share with Board, Share Care Council members.

2. Share the SCC group picture among members for personal use only

- Continue to respect confidentiality of SCC members' participation.

APPENDIX A: AGENDA

SHARE CARE COUNCIL



DATE: Saturday, March 4, 2017
TIME: 9:30am – 2:00pm
LOCATION: Homewood Suites
 2095 Winston Park Drive
 Oakville ON L6H 6P5

OUTCOMES:

- Review of activities to date
- Recognition and celebration of achievements
- Conclusion of mandate

Item	Agenda Item Description	Time	Lead
	Breakfast	9:30am–10:00am	All
1.0	Opening remarks and overview of the agenda	10:00am–10:20am	Marian Pitters, Facilitator
2.0	Update on progress since December 2016 meeting	10:20 am – 10:45 am	Nancy Gale, AVP Communications & Kathryn Hales, Patient Relations Associate
3.0	What has worked well for the inaugural Share Care Council and what would your advice be to improve the structure of future advisory groups?	10:45 am – 12:30 pm	All
	Lunch	12:00pm–12:30pm	
4.0	Recognition of Share Care Council achievements	1:00 pm – 1:45 pm	All Members
5.0	Final reflections	1:45 pm – 2:00 pm	Marian Pitters
6.0	Adjourn meeting	2:00pm	All

APPENDIX B: TERMS OF REFERENCE



SHARE CARE COUNCIL

TERMS OF REFERENCE

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 (on what? Be specific) 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/carers 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.
- 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 patient and carer populations (approximately 20).
- Meetings will be Facilitated by an external consultant

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).
- Terms of Reference/ Membership to be reviewed annually

MEETINGS

- Four meetings annually
- The agenda 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. If the meeting is attended by 50% of the membership, decisions hold.

APPENDIX C: GUIDELINES FOR SHARE CARE COUNCIL DISCUSSION - MISSISSAUGA HALTON CCAC

Participants 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.

- 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.