

**Meeting Outcomes**  
from the

**Share Care Council**

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**September 19, 2015**

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## **ACKNOWLEDGEMENTS**

Thank you to participants for their on-going commitment and guidance to the people served by Mississauga Halton CCAC.

Nancy Gale, AVP, Strategic Communications and Partnership Advancement, Mississauga  
Halton CCAC

Joanne Gougeon, Executive Assistant, Mississauga Halton CCAC

Marian Pitters, Facilitator, Pitters Associates

Karen Metcalfe, Senior Consultant, Pitters Associates

## EXECUTIVE SUMMARY

On Saturday September 19, 2015 the Mississauga Halton CCAC hosted the sixth **Share Care Council** (SCC) meeting. 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 for community based health care. This purpose supports the first strategic direction of the CCAC's strategic plan for 2015 – 2020: Meaningful Experiences & Outcomes.<sup>1</sup>

To open the session, Don Taylor, Chair of the Patient Care Quality Committee of the Board, welcomed everyone and conveyed the Board's thoughts on the SCC: *"We are REALLY impressed with this group. Although you have only been in existence for a short time, you have developed quite a reputation with our partners and administration. Your work on seamless transitions is remarkable! You are developing a lot of respect in the region."* He highlighted specific examples where the SCC has had an impact and encouraged the members to continue their important contributions: *"You have helped reduce the re-admits to hospital by over 50% - that is unheard of and impressive. You contribute a lot of value. Please keep up the good work."*

Lara De Sousa, Director Patient Care, echoed Don's remarks and requested the SCC's advice on a specific program of work about a new framework for care coordination: *"a real discipline and art, not an administrative function."* Lara indicated that the SCC's input about care coordination was needed on: what it means, how the front-line execute it, the competencies required and the tools needed to build those competencies. *"Your insights and feedback are going to be critical to inform what we are seeking to do."*

Marian Pitters, the facilitator, presented a brief history on the SCC: how it was formed, the terms of reference and discussion guidelines (see appendix), and the accomplishments since March 2014:

- Recommendations regarding my service provider's job (PSW); family member's role
- Navigating the system – Patient and Caregiver Bill of Rights
- Your care with your family doctor
- The experience from hospital to home –Seamless Transitions

Nancy Gale, the AVP, Strategic Communications and Partnership Advancement, provided an update on progress since the June 2015 SCC meeting and addressed questions of clarification. She highlighted the following:

- Seamless Transitions project is in the planning stages for implementation at all hospital sites in Trillium Health Partners; it is being implemented at Halton Healthcare Services – Georgetown Hospital, starting in September 2015
- The Patient and Caregiver Bill of Rights is going to the Board on October 7 for information and then will be published. Partners are interested in the Bill because it was created by patients and families.
- "What is the PSW's job?" was shared with service providers. They are trying use it to improve patient satisfaction - it's not only important what you provide, but how you provide it.

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<sup>1</sup> See

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

Nancy concluded with: *“We’re listening and congratulations on making such a difference.”*

Following introductions, the rest of the session focused on providing guidance on the new opportunity: care coordination. This report summarizes the meeting highlights, the details of which are appended. The feedback summary indicates that participants thought the outcomes for the session were achieved and also appreciated the open and respectful dialogue. They continue to feel valuable and important, and look forward to the SCC meetings. The meeting “veterans” ended the day by thanking the new members for *“giving us a try. We really appreciate the new ideas.”*

## NEW OPPORTUNITY: CARE COORDINATION

The first step is to identify what patients and caregivers really need from this single point of contact called a care coordinator.

To this end, participants responded to the following five questions about care coordination:

### 1. When you are at home, what would your ideal relationship with your care coordinator be?

SCC members' responses clustered into four themes, some of which overlap:

- Communicate the roles of the CCAC, care coordinator and other providers that ensure consistent delivery of care
- Match service delivery to needs, especially during transitions
- Use the latest technology
- Include patients and caregivers in care planning.

### Communicate the roles of the CCAC, care coordinator and other providers that ensure consistent delivery of care

- Widely communicate the role of the CCAC in treatment plans so it trickles down to service providers in all parts of the system and to all patients and caregivers. "My physicians hardly know what CCAC does; patients like me don't know what CCAC is or what a case manager does."
- "I feel like I have been invited into a secret society – this is an amazing organization that is hiding"
- Make clear who is responsible for what in hospital and in the community. Right now there is confusion, misunderstandings
- Offer flexibility between service boundaries, e.g., in-home services over a long period of time, palliative care. Situations are not cut and dry – don't always fit and there is movement back and forth. How does my care coordinator help my mother in the grey areas between care and palliative care? I need my care coordinator to open that conversation with me.
- Spread the word about the functions of the care coordinator "hub", e.g.,
  - Be the hub of the wheel so that caregivers don't become the hub of the wheel - a resource centre that replaces Google – "this is what I'm looking for, can you help?"
  - Be the person who is familiar with my case and can help me through the changes
  - Help maneuver through the maze and save time: "I'll find out for you."
  - Care Coordinator as more than a trouble shooter when there is an issue to resolve
  - Communicate the expectation of the next visit / next steps
  - "If it weren't for me, we couldn't have navigated the system because I'm in healthcare. I wanted to be the daughter but I couldn't be; I had to be a navigator."
- **Share Care Council** members quickly and enthusiastically embraced the concept of the care coordinator being the coordinator for everything in the system. Note, members rallied behind the concept of a 'paradigm shift' – where the care coordinator moves from coordinating my health and social services to helping me on my journey **from illness to wellness**) From the beginning, introduce the care coordinator role as the person who oversees everything, so individuals like my doctor, my specialist know who to contact

when there are issues. This works well in palliative services but not in short-term services.

- Ensure care coordinators are consistent – we need care coordinators who can establish great rapport, make us comfortable and know the patient and family vs. having a revolving door of care coordinators.
- If a change in service providers needs to happen, give the new service provider person providing the care a summary of the situation they are going into. The relationship between the patient and service provider improves quality of service.

### **Match service delivery to needs, especially during transitions**

- Establish a timeframe for the first at-home meeting – do things right away within one or two days. Waiting a week is too long. Get on the phone and call.
- Talk first, in a timely way, then deal with the task.
- Tell us what we are ‘entitled’ to, what we are getting (how many hours, who is coming) rather than negotiating when we are desperate. Inquire about what our needs are and tell us everything that is and/or will be available, e.g., if your status changes, these are other things we provide that you might need.
- Offer guidance when patients are making decisions; be our advisors.
- Be well informed of available equipment options, especially if something isn’t working; connect to the proper people that can help find a solution.
- Determine if various levels of care coordinators will be required for different situations, e.g., an elderly person with no family, a child moving into the adult system. Match the type or level of care coordinator to the vulnerability of person.

### **Use the latest technology**

- Introduce one access point and technology that could help make an individual’s story complete, even when the family loses the record or moves. It would allow the CCAC to help from a distance and provide trustworthy information.
- Provide email option for documents (This was particularly important for caregivers.)
- Use newer technology, e.g., video technology could allow care coordinators to touch base more often.
- Make assessments portable so they follow the patient: assessments done by one care coordinator should be respected across Ontario and by other CCACs and care coordinators.

### **Include patients and caregivers in care planning**

- Provide a paper record of the care plan highlights:
  - Send a copy of information with the patient or caregiver, e.g., from hospital to home – what has been ordered vs. all plans and records are somewhere at CCAC so there is a disconnect with the family
  - *“Currently there is no paper work - it is in my memory what the person says. If I am not there, no one would know.”*
- Plan with the patient and family as much as can be anticipated in advance; and follow-up.
- Clarify what the care coordinator is going to do to make me a partner in my care, e.g., together we move me from illness to wellness (this is the paradigm shift referenced above.). If that is the premise that the meeting began on, that would change the model entirely. Match the situation and information to my needs and adjust as they change. Sometimes too much information isn’t helpful, e.g., when in a critical situation I don’t want all the information but when I need a new wheelchair, I want all the options.

- “No one treats me like a partner, is this my role?”
- Patient needs to be responsible to share need/ situation as things change

## 2. What parts of the Care Coordinator role are working now that you want to protect?

- Regularly schedule meetings that are appropriate for each individual’s situation, e.g., every three months, or more frequent if acute.
- Maintain the advocacy relationship between the 3<sup>rd</sup> party service provider (home care nurses, etc.) and the care coordinator, with the addition of the patient or caregiver being included in the feedback of what has been discussed and decided. Once the third party service provider has talked to the CCAC, report back to patient and caregiver.
- Watch our backs for the future – thinking ahead for what we need to deal with during transitions, e.g., helped my son as we approached milestones. “Sometimes you don’t know what to expect so you don’t know what to ask for, e.g., child to youth to adult; illness to wellness; illness to palliative.”
- Service provider organization and care coordinator communications – call ahead with a time window for visits, or when arriving and delayed. Don’t make people sit and wait.
- Protect the role of the care coordinator, e.g., include the care coordinator in other exchanges and programs patients are involved in, e.g., breast cancer and prostate cancer apps (This is a reference to other monitoring devices for cancer patients. If the care coordinator is the coordinator for the patients care and journey to well-being, then that care coordinator needs to receive all health information about me. This is a missing element today as oncologists, medical device companies, etc. don’t include the care coordinator. So the care coordinator does not have a complete picture and he/she needs to have that information. As a patient, what can we do to help ensure those connections to our care coordinators are made and that he/she really is a member of my circle of care?

## 3. What information would you like from your care coordinator so that you are comfortable with your care?

SCC members provided examples of information that are captured in two themes: service delivery and the health care system.

- **Information about service delivery:**
  - Paper records of care
  - Emails
  - Advice
  - Assessment
  - Bring together records – I want to see my health file – it’s about me!
  - Resource hub
  - When you will see them next
  - Summary of individual evaluations
  - Form of information is important – reader friendly, understandable. No medical-ese. Help ensure that all information is in the proper form for patients. Filter or curate the information so it is “need to know.” Or explain it to me in a way I can understand.

- **Information about the health care system:**
  - Who to talk to and how to get to them
  - How to give and get feedback about services
  - Who is responsible for what?
  - How to arrange for transferring assessments across Ontario's CCAC regions
  - Who gets the information about patient and caregivers?

#### **4. What information would help you participate in your care?**

- A summary of my situation to be reviewed by new service providers prior to their first visit
- Service delivery and equipment options, especially during transitions when needs are changing
- A brief overview of the health care system and the role of the CCAC within that; who is responsible for what, where?
- The functions of the care coordinator at home and from hospital to home
- How care planning will unfold into the patient's future, anticipating changing needs
- Information that can contribute to informed decisions about care – be my advisor
- How to arrange for continuous service across CCAC boundaries in Ontario

#### **5. What would you want to know after a care conference and how could this be communicated to you?**

Participants discussed the care conference in terms of what they would like to happen before, during and after the meeting. They focused more discussion on what went on before and during the care conference than afterwards, perhaps because they had addressed “afterwards” in the previous questions.

Participants asked for a definition of a care conference; this language was not understood.

There was robust conversation about a meeting with health professionals where patients and caregivers would not understand the language used in the conversation by health professionals and they would feel intimidated. Some wanted to be present; however, by the end of the lively discussion, participants determined the value of a family meeting – referencing Lara's suggestion that important people may be the PSW, the neighbour – and that ‘patient and family’ meeting should be with the care coordinator who can learn their wishes, their fears, their goals and then advocate for them in the care conference with doctors, specialists and other health professionals.

#### **Before a care conference:**

- Clarify difference between a care conference and a family meeting; if the care conference is a family meeting - must be there
- Two ideas - family must be there OR family must be followed up with after
- Ensure people attend who are going to be the resource when the patient is at home or when patient leaves the hospital

**During a care conference (note the difference between the clinical care conference and the ‘family meeting’):**

- For the in-hospital care conference, identify the care coordinator and phone number (no central numbers). The CCAC is daunting for people, there is uncertainty. In complex cases, ensure my care coordinator is at the hospital meeting
- For the at-home care conference, ensure it takes place after two days at home (not a week later); need family meeting with the care coordinator, doctor, service providers that are key, e.g., (OT, PT, PSW, Nurse), supervisor (ensures transparency – upfront at launch of service - who is going to do what), patient, others that the family thinks are or will be involved, e.g., family friend, neighbour, pastor, who can help. Utilize conference calls with everyone at the same time, all at once vs. when we arriving home from the hospital it takes two weeks of calls with different people before we get settled
- In the care plan, document a “to do list” of what is going to be done and who is going to do it and have that communicated to all involved, e.g., clarify what is going to happen up to a certain date, service for how long.
- Clarify expectations regarding what the family expected to take on over time vs. expectations are sprung on us and it is too much
- Do not say “our goal is to discharge” at first visit - very scary for people – say ‘our goal is to get you as well as you can be.’
- Provide an overview of the types of insurance; an example includes, “I need help from a social worker for my depression and someone to help me with my body image issues after my cancer surgery – I was so depressed. You may not be able to pay for it, but I need you to see that I was depressed and that I need you to make this suggestion and where/how I can get help.” Another example, “I need housekeeping services; I am now in a wheelchair. I want someone trustworthy in my home; help me find someone, even though you are not providing it to me. I know I must pay or my insurance will pay. I need you to help me feel safe at home and not have strangers who are not bonded and insured coming in.”
- Realize that not everyone can step up to the plate when contending with emotional stress, e.g., I was expected to give my husband insulin. I’m a wife, not a nurse.
- Ask more questions to adapt to individual needs of patients, not leaving it up to family
- Explain how services are increased, decreased or stopped for some types of patients, e.g., you come out of hospital and PSW services are evaluated and redistributed. Needs change as people recover at home

**After a care conference:**

- Follow-up with patients to translate what went on, if there is much “medical-ese”. 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 that could not attend, and other stakeholders

**2. Send out all previous reports (by email) to new Share Care Council members****3. Prepare for next meeting in January (date to be determined):**

- Where: Homewood Suites, Oakville
- Agenda:
  - Role of family member – re-visit
  - Explore and redesign care for individuals with a life threatening illness who are receiving palliative care – the experience in our region
  - Review patient information package – an outcome of Patient and Caregiver Bill of Rights and is part of Care Coordination Program of Work
  - Review caregiver support package – an outcome of Patient and Caregiver Bill of Rights

## **APPENDIX A: INTRODUCTIONS**

The SCC discussion began with each member sharing their response to one of two questions posed. The question for veterans was, “*what interests you most about SCC?*” New members were asked, “*What are you looking forward to the most about SCC?*” Below are the responses they shared:

### **What interests “veterans” most about SCC:**

*My mother is going to be 90 and lives with me. What everyone says is what interests me.*

*I think it's very important that our input is valued – that's what interests me the most. Palliative care is of most interest to me.*

*I've really enjoyed being part of this. I was so nervous at first thinking what I could offer and now I see the changes we have made. It's really exciting.*

*I found this extremely interesting, how others deal with their issues and how the needs are being addressed.*

*I wasn't sure at first. It has been interesting and seeing the results and our ideas acted on.*

*I was scared when I first came wondering what I had to offer and its really good to hear how the things we talk about get turned into something. This isn't just talk, its effective.*

*I close my eyes when I am here and pretend I am the patient and it always takes you to a good conclusion.*

*It is a very good way of communicating between those who get service and those who supply service. It's a good way to come together from time to time.*

*I'm curious to know how SCC all came about and who is on the committee. I come from two different perspectives: I've benefited from a personal point of view as my mother was palliative; and, I'm also a healthcare provider. I'm very interested in being a part of SCC.*

### **What “new members” are looking forward to the most about SCC:**

*Thank you for inviting me. I'm not sure why I'm here but I'm pleased to be here. I'm a colon cancer survivor, been actively involved with CCAC for two years and involved in a number of ways. I look at this as an opportunity to pay it forward.*

*I want to be involved with stakeholders. I had a very bad experience as a patient and was charged \$20 an hour by a person that was not legal. I didn't know what services CCAC provided until I got referred. I thought the CCAC only sent a nurse. The CCAC put me in touch with people that can be trusted in my home. I look forward to more education. I like bringing the people responsible for my care into the equation.*

*To know how the machine runs is very interesting to me. It's the centre of my world and it means a lot to the people who receive the care. It's the highlight of my day – it's the centre of my world. I never knew you could get so addicted to showering.*

# APPENDIX B: SEAMLESS TRANSITIONS: HOSPITAL TO HOME

## Seamless Transitions: Hospital to Home

### Quick Facts



<b>Project goal</b>	To develop a consistent, integrated, patient-centered approach for hospital to home transitions that improves patient experience by eliminating duplication in processes and reducing gaps in care that put patients at risk.
<b>Problem statement</b>	We lack a shared understanding of patients' needs to inform and execute a care plan that will give them confidence to leave hospital.
<b>Partnership Principles</b>	Values & Accountability   Trust-Based Interactions   Courage to Innovate

### Background – Partnering for patients

The Mississauga Halton Community Care Access Centre (CCAC) and Trillium Health Partners (THP) established a formal partnership to improve the way patients are cared for in the region. The first innovation initiative is *Seamless Transitions: Hospital to Home*.

Using insights from patients, families, physicians, hospital staff, CCAC staff, service providers and a leading practice review, a new hospital transition approach was designed by a dedicated interprofessional Design Team, comprised of staff from THP and the Mississauga Halton CCAC.

The new *Seamless Transitions* approach began testing September 29 at Trillium Health Partners-Credit Valley Hospital in the Medicine program, and will continue testing until May 31, 2015.

During the first 12 weeks of testing, the *Seamless Transitions* care team cared for patients on one physician caseload. On January 26 2015, the test phase expanded to include patients on a second physician caseload, doubling the number of patients in the test group and helping gain further valuable insights with a larger patient population.

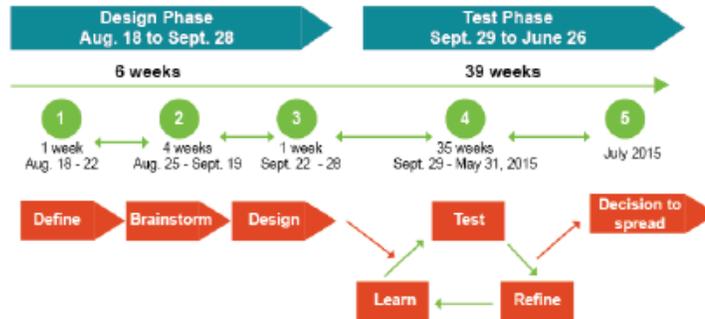
### Design process and timeline

#### Design Phase

(Aug. 18 to Sept. 28 - six weeks)

#### Test Phase

(Sept. 29, 2014 to May 31, 2015 - 39 weeks)



## APPENDIX C: STRATEGIC PLAN 2015-2020

## APPENDIX D: AGENDA

### SHARE CARE COUNCIL



- DATE:** Saturday, September 19, 2015  
**TIME:** 9:30am – 2:00pm  
**LOCATION:** Homewood Suites,  
 2095 Winston Park Drive, Oakville ON L6H 6P5  
**OUTCOMES:**
- Welcome new members
  - Update progress on priority topics
  - 2015-2020 strategic plan priorities
  - Discuss next steps

Item	Agenda Item Description	Time	Lead
	Breakfast – Happy New Year!	9:30 am – 10:00 am	All
1.0	Opening remarks	10:00 am – 10:20 am	Lara De Sousa, Director & Don Taylor, Board Member
2.0	Overview of agenda <ul style="list-style-type: none"> <li>• Welcome new members and an overview of principles, work completed to date</li> </ul>	10:20 am – 10:45 am	Marian Pitters, Facilitator
3.0	Update on progress since April meeting:	10:45 am – 11:00 am	Nancy Gale, AVP
4.0	2015/2012 Strategic Plan <ul style="list-style-type: none"> <li>• Overview of new strategic plan</li> <li>• Introduction of strategic priorities/upcoming topics</li> </ul>	10:00 am – 12:00pm	All
	Lunch	12:00 pm – 12:30 pm	
5.0	Care Coordination <ul style="list-style-type: none"> <li>• Question to be confirmed</li> </ul>	12:30 pm – 1:45 pm	All
6.0	Next steps <ul style="list-style-type: none"> <li>• Think ahead to next meeting</li> <li>• Meeting evaluation</li> </ul>	1:45 pm - 2:00 pm	Marian Pitters
7.0	Adjourn meeting	2:00 pm	All

# APPENDIX E: PATIENT AND CAREGIVER BILL OF RIGHTS

As Mississauga Halton CCAC patients and/or caregivers, we have the right to:

**1. Be in charge of decisions about our agreed upon care plan – no decision about us, without us.\***

- 1.1 Discuss our needs, goals, and options for treatment and service within timelines
  - A detailed care plan starting with my needs and showing my care goals and timelines; frequency of assessment as required.
- 1.2 Identify who is providing what care, when
  - Agency name, contact person, phone number, service provider's name/role.
  - Access to consistent care
  - Access to consistent service across CCAC boundaries.
  - Access transition support that ensures consistent and continuing service across care settings within the health system.
- 1.3 A patient can refuse recommended service or elements of the care plan without reprisal on future care, unless otherwise provided in law.

**2. Clarify how we will all work together (me and my care team) to carry out the care plan**

- 2.1 Communicate for understanding
  - Use multiple languages images/visuals, clear medical terminology, etc., as required for understanding
- 2.2 Respect each other, our physical privacy, homes and lifestyles
  - Speak without "talking down".
  - During showering or treatment close the window blinds, close the door, cover me up.
  - Return things to their proper place.
  - Discuss pet management with the care team on an individual basis, so that all parties are comfortable.
- 2.3 Report abuse, harassment, bad care
  - Provide direct contact information to a CCAC Care Coordinator for reporting.

**3. Get assistance beyond the care plan, when we need it.**

- 3.1 Provide one page that summarizes key care team contact numbers.
- 3.2 Provide one phone number to a CCAC Care Coordinator for appropriate on-call medical help and support or a service provider (other than 911 or the health hotline). Include the Mississauga Halton Health Line information.
- 3.3 Provide an updated, one page summary of the care plan and medications for emergency purposes.

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\* The origin of this phrase is the Latin "Nihil de nobis, sine nobis". It has been used for decades by a number of groups involved in health and disability issues internationally.

# APPENDIX F: TERMS OF REFERENCE



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## SHARE CARE COUNCIL

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### **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 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. If the meeting is attended by 50% of the membership, decisions hold.

## APPENDIX G: SUMMARY OF SESSION FEEDBACK

All twelve 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 achieved:

	1 Poor	2	3	4	5 Excellent	Did not respond	Average
Welcome new members	0	0	0	1	10	1	4.9
Update progress on priority topics	0	0	0	2	9	1	4.8
Provide an overview of 2015-2020 strategic plan priorities	0	0	1	4	6	1	4.5
Determine next steps	0	0	1	4	6	1	4.5

### 2. What participants found most useful about the session:

- Open dialogue and respect for views of all (5)
  - Great to have input from new members
  - That every experience is different and input was appreciated for delivering best care
- Very informative and detailed; updates (3)
- That our words turn into action (3)
  - Hearing how you took our input and used it to change/improve things at hospitals, CCACs.
  - Useful to know that an effort is being made to consolidate all aspects of a patient's health care. Once started, patients' health story will follow them as they go from home to hospital to community-based care to family doctor to specialist to physio, etc.

### 3. Words of advice for this year's Share Care Council sessions:

- Keep the process and opinions open; keep the ideas coming (2)
- Helpful if each person introduces self and why there, .e.g., patient, caregiver
  - When adding new members ask everyone to give quick background of interest/connection to CCAC, e.g., cancer patient, mother of disabled child, daughter of senior
  - A copy of the session notes from September for this novice – I still feel as if I'm in a whirlpool!
- Agenda logistics (2)
  - Extend time 9:30-2:30
  - Leave time in agenda (30 minutes) for attendees to summarize their thoughts of the session
- Some stats on the situation for palliative
- Be more reasonable

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

- It was great to see so many of our thoughts in the strategic plan
- We are putting much emphasis on work coordinator, what about family members' responsibilities
- The facilitator is great at giving us all a chance to talk and tell our story
- Looking forward to the next session
- We missed the opportunity to redefine the care conference. It should not be a treatment/care model – it should be focused on a journey to wellness!

- Soon the doctor won't need to see the patient in person, just interface with the computer. Patient-centred care may have a different look in the near future.

**5. Other comments:**

- Good meeting; it is quite useful (3)
- Very excited about being part of this.