

# Complex Care Family Engagement Sessions

## *Letter to Parents*

Dear Parents,

Thank you for your time in meeting with us to share your stories and more importantly to discuss what is needed to improve care and coordination for children with medical complexities. Many of you took the time out of your busy schedule to meet us at Children's Hospital – LHSC, Children's Hospital of Eastern Ontario (CHEO), and McMaster Children's Hospital because you knew how important it is for us to discuss these issues with family members, health care providers, community providers, and policy-makers all together in a room. We heard from you, and I hope that we have capture most, if not all, of your concerns and challenges. It does not stop here, we will use what we heard to work collaboratively and design a model of care and coordination that is family-centred with you in mind.

We will continue working with health care providers to improve care for your children. We will continue to develop plans, tools, and resources to help providers improve collaboration and communication. We will continue to raise awareness and advocate for children with medical complexities to

It is important to note that although many barriers and challenges were discussed, there was also a lot of great work that is currently being done. The complex care teams are composed of very dedicated and passionate group that have been caring for these patients for many years. Many parents were very appreciative for the care that is provided.

Thank you parents for your time and input, this will be one of many engagement sessions and we look forward to meeting again.

- CCKO Project Management office
- Children's Hospital – LHSC Complex Care Team
- Children's Hospital of Eastern Ontario Complex Care Team
- McMaster Children's Hospital Complex Care Team



# Family Engagement Session Summary

The Provincial Council for Maternal and Child Health (PCMCH) partnered with Children's Hospital - LHSC, Children's Hospital of Eastern Ontario (CHEO), and McMaster Children's Hospital to hold engagement sessions with families and providers of children with medical complexity. The objectives were:

-  To share with families the implementation of the CCKO strategy and to hear from the complex care team at the children's hospital
-  To provide an opportunity for families to share their stories and draw on their experiences to have an informed discussion about medical care coordination in Ontario
-  To discuss what is needed to improve child and family-centred care for children with complex care needs receiving services through McMaster Children's Hospital

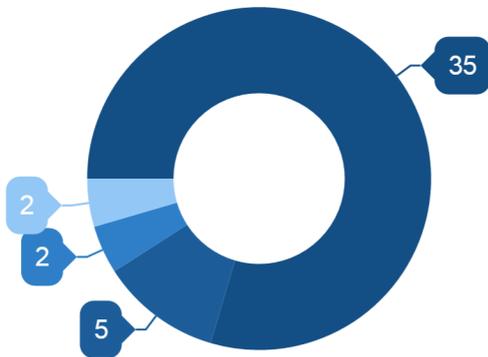
-  3 family engagement sessions
-  53 family members
-  66 health care providers and community partners

The full day sessions included a mix of activities including family stories being shared, discussion on what's working well and what could be improved, and a mapping exercise to understand the current state of the parents' journey through a complex care clinic visit. On the next page is a visualization of what we heard from parents throughout the regions. For more detailed regional findings please see separate family engagement reports from each of the regional sessions..

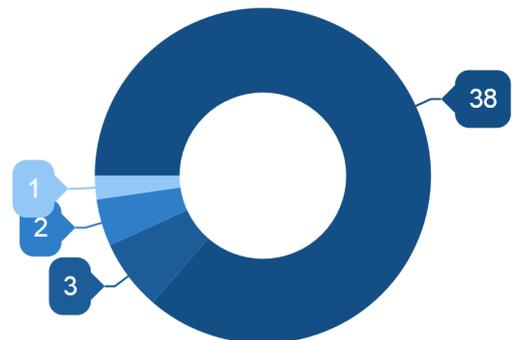
## Evaluation Feedback

Based on evaluation feedback, most attendees felt the family engagement session was beneficial and would recommend this family engagement session to others. Many families indicated that they would like these family engagement sessions on a regular basis and appreciated the ability to have the opportunity to meet with staff and discuss ways to improve care and coordination for children with medical complexity.

Overall the family engagement session was informative and beneficial



I would recommend this family engagement session



■ Strongly Agree (80%) 
 ■ Agree (11%) 
 ■ Disagree (5%) 
 ■ Strongly Disagree (5%)

■ Strongly Agree (86%) 
 ■ Agree (7%) 
 ■ Disagree (5%) 
 ■ Strongly Disagree (2%)

# A Parents Journey Through a Complex Care Hospital Visit

## Scheduling Clinic Appointment

coordinating multiple appointments on one day

- find child care for other siblings
- reschedule nursing hours
- schedule time off work
- book transportation

## Travel and Parking

needing to make sure all bags and equipment are packed in the car

appointment times too early for out of town patients

long commutes, having to stop for suctioning

high cost for parking

lack of accessible parking spots

## Registration and Check-In

repeating information

lack of accessible doors, washrooms

difficulty finding clinic location

## Waiting

agitation from many stimuli

long wait

exposure to illness and infection

lack of accessible space

## Multiple Care Provider Appointment

repeating the story again and again to multiple providers

unprepared students

waiting for doctors or specialists to arrive

## Tests/Re-Tests

anxious about results

long wait

issues with rescheduling appointments

confusion with requisitions

## Travel Home

traffic

feeling tired

# What's Next and How Else to Be Involved with CCKO

We are continuing to work with each of the regions to enhance and expand the complex care clinics to serve more children with medical complexity. We are working together to provide care closer to home. We are meeting regularly to discuss ways to standardize care across the province. We are engaging the full continuum of care and service providers (i.e. hospital, community care, rehabilitative services) who support children with medical complexity.

But more importantly we want to continue hearing from families! Here are a few ways to do just that:

## Share Your Stories With Us

An important part of CCKO is to share the stories and testimonies of family with complex care children. We are working together to create a collection of written, audio, and video stories. Please contact Allison Chiu ([allison.chiu@pcmch.on.ca](mailto:allison.chiu@pcmch.on.ca)) for more information on how to submit your story.



## Save the Date: CCKO Provincial Symposium

Please join us on Thursday February 9, 2017 for an all day symposium to share and discuss what the work that is happening in Ontario related to complex care. This will be a day full of shared learning, relationship building, and collective advancement towards the shared vision for integrated care and service coordination. Families, health care providers, administrative leaders, and community stakeholders will be in attendance. Registration opens November 2016. More details to follow on our website.



## Join our E-Mail List

For up to date news and events please join our mailing list. Contact Allison Chiu ([allison.chiu@pcmch.on.ca](mailto:allison.chiu@pcmch.on.ca)) to be added to our list.



## Follow us on Social Media

Let's be social! For up to date information on what is happening and related news and events, follow us on social media and share with us what is happening with you.



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Provincial Council for  
Maternal and Child  
Health

Alone we can do so little, together we can do so much.  
- Helen Keller