Collaborating with Caregivers to Evolve the Toronto Central Integrated Palliative Care Program

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Session Outline

• Why Now? Why Collaboration?
• Establishing the Client/Caregiver Panel
• Creating the Foundation for Collaboration
• Achieving Tangible Results
• Continuously Evolving our Approach
• Conclusions, Next Steps & Advice
• Questions & Answers
Why Now?
Why Collaboration?
Toronto Central CCAC Strategic Plan (2012-2016)

**Strategic Direction 1**
We will relentlessly pursue every option to deliver what is most important to every client

“Talk to me to find out what’s most important.”

**Strategic Direction 2**
We will support our clients to live the fullest and healthiest lives possible

“I knew life was going to be different, but it’s nice to know it doesn’t have to be completely different.”

**Strategic Direction 3**
We will unleash the potential of our people

“I’m proud to work at a place where at the end of the day, I know I’ve made a difference in people’s lives.”

**Strategic Direction 4**
We will drive the highest possible care integration for our client populations who need it most

“I meet with my CCAC Care Coordinator every two weeks or so and last time she arranged for my doctor to come with her.”

A strategy dedicated to client experience, quality improvement, and integration with a focus on advancing the home and community care sector
Focusing on what’s most important to our clients in everything we do

We will relentlessly pursue every option to deliver what is most important to every client.

"Talk to me to find out what’s most important."

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Changing the Conversation - Asking our clients what is most important to them

Advancing Client Flexibility & Choice

Partnering with Clients to co-design programs and services
Evolution of the Palliative Care Program Up to 2015

Listening to Our Clients…

…Driving Improvement

1983-1988
Home Based Care (HIV/AIDS)

1998-2009
Consult Model

2009-Present
Population-Based Model

2010-Present
One Number

2010-Present
Palliative Huddles

2010-Present
ICCP

2012-Present
Palliative Nurse Practitioner Program

2012-Present
VOICES Survey (2012-2014)

2014 to Present
Dedicated Geographical Provider Teams

2014 to Present
Integrated Care Teams

Present

Provincial declaration of partnership on Palliative Care (2011)

Toronto Central LHIN Palliative Care Strategy (2014)

ICCP and Changing the Conversation Surveys (2011)

Palliative Client and Caregiver Survey (2010)
Continuum of Client Engagement

(Original Source for Continuum: International Association of Public Participation, IAP2 Public Participation Spectrum)

Integrated Palliative Care Program Opportunity

• Partners established a new program vision in 2015 to work as an integrated program and provide high-quality, client-driven care

• shared commitment to collaborate with caregivers & clients to shape the prioritization, design & implementation of strategic improvements required to achieve this vision
Establishing the Client/Caregiver Panel
Shared Leadership Approach

Program Leadership

Engagement Facilitator
Comprehensive Participant Identification Process

1. Program partners identified 16 clients/caregivers who may be interested in participating in this work.

2. Phone conversation with each candidate to help them understand our goals and determine how they want to be engaged.

3. Confirmed 6 clients/caregivers who were interested and able to participate in co-design and program improvement.
Why it was Important to Participate
Creating a Foundation for Collaboration
Objectives:

• to provide advice to the Integrated Palliative Care Program related to the prioritization, design and implementation of program improvements

• to test the advisory panel approach

Starting Point:

• 6 participants (1 client, 5 caregivers)

• 6 monthly meetings, timing based on participant feedback

• 3-4 program leadership attendees, 1 facilitator

• Commitment to explore opportunities for co-design working groups to advance improvement priorities
Building Relationships

SHARING

EXPERIENCES

STORIES

LISTENING
Panel members indicated that ‘meaningful engagement’ of clients and caregivers in program improvement would:

- Enable panel members to roll up their sleeves and help making a concrete, positive, difference
- Demonstrate that we are being listened to and that our contributions are reflected in the actions of the program
- Translate contributions into tangible outcomes and improvements for clients/caregivers supported by program
Achieving Tangible Results
Tangible Result #1:
Informing Program Priorities & Identifying Additional Opportunities

**Improvement Opportunities Identified by Panel**

1. Integration & communication
2. Better access to 24/7 specialized palliative supports
3. Better access to a full range of verbal and written information
4. Improved caregiver supports
5. Improved PSW service

**Improvement Opportunities Identified by Steering Ctee.**

1. One integrated care team
2. Cross continuum care
3. One electronic medical record
4. Single access point with one number
5. 24/7 access to the care team

Meeting 2 & 3
Tangible Result #2: Working with Program Partners to design a new Info Kit

Program Steering Committee

Partner Focus Group

Virtual working group

Client and Caregiver Advisory Committee

Panel Focus Group

Co-designed Information Kit

Inform  Consult  Involve  Collaborate  Empower

Meeting 4
Tangible Result #3: Concrete Advice that is Informing Improvement Work

**Caregiver Support**
- What ‘caregiver support’ means
- Improvement ideas & priorities

**EMR Transition**
- The written information, specific to their own care & services, that clients/ caregivers should receive

**24/7 Access to Care Team**
- Ideas for streamlining access to the integrated care team members

Meeting 5
- Meeting 6
- Meeting 7
Continuously Evolving Our Approach
Initial Approach for Panel Meetings

- Designed to achieve specific objectives
- Panel-informed agenda topics
- Meeting Room at TC CCAC
- Materials circulated in advance
- Share how feedback is being used
- Reimburse for Travel
What TC CCAC Staff Observed

• Agendas were too ambitious the first few months.

• Facilitation of group discussion was important

• Takes time, commitment & resources to do engagement well

• Advice had relevance beyond the program’s scope
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<tr>
<th>What Worked Well</th>
<th>What Was Challenging</th>
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<tr>
<td>• Clearly set expectations</td>
<td>• Meetings are hard; discussions bring up a lot of emotions</td>
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<td>• Meetings and materials very organized</td>
<td>• There is more to share than is possible with six perspectives to hear</td>
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<td>• Everyone has a chance to speak</td>
<td>• At times the discussion goes on tangents but team keeps us on track</td>
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<td>• Supportive environment for sensitive conversations and different opinions</td>
<td>• Access to the building from the parking lot for those with mobility limitations</td>
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<td>• Staff is genuinely committed to improving – not just talk</td>
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Acting on Panel Members’ Suggestions

✓ Acknowledge that conversations may be difficult
✓ Create more of a lounge experience
✓ Keep using name tags/place cards
✓ Solve the access issues from parking lot
✓ Slow down when presenting the slides
✓ Revisit list of improvement opportunities
✓ Explore opportunities to do journey mapping
Conclusions,
Next Steps &
Advice for Others
Our Outstanding Client & Caregiver Palliative Care Advisory Panel
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<tr>
<th>TC CCAC Perspective</th>
<th>Program Perspective</th>
<th>Caregiver Perspective</th>
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<td>• Continued learning on how to effectively engage and collaborate with caregivers</td>
<td>• Caregiver voice has created new insight &amp; understanding that is undoubtedly influencing program improvements</td>
<td>• Harder emotionally than anticipated — but worth it to help improve things for future patients, families and caregivers</td>
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<td>• Inspiring caregiver and patient engagement by other programs &amp; informing the approach used</td>
<td>• Collaborative work generates high value</td>
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<td>• Impressed by the commitment &amp; generosity</td>
<td>• 100% of members feel participating is a meaningful use of their time and want to continue</td>
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## Next Steps

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<th>Summer 2016</th>
<th>Fall 2016</th>
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<td>• Celebration &amp; Recognition</td>
<td>• Extend Advisory Panel &amp; transition to quarterly meetings</td>
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<td>• Continue to act on feedback received to date</td>
<td>• Focus on advancing more collaborative working groups,</td>
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<td>starting with caregiver support</td>
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<td>• Develop Formal Terms of Reference</td>
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Our Emerging Advice

1. Don’t be afraid to start

2. Be clear on purpose & commit to the appropriate type of engagement

3. Leverage recruitment to match applicant & program interests/expectations

4. Define what ‘meaningful engagement’ means from the participants’ perspective and commit to demonstrating that this is being honoured

5. Invest in facilitation for group discussions

6. Seek regular feedback from participants
Comments? Questions?

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