Welcome to the RGP of Toronto network webinar!

The presentation will begin in a few moments. Here are some tips:

• To ask a question during the webinar, type into the “Chat” box

• A fast, wired internet connection is best – slow connections might cause poor reception and gaps in audio or video

• Please use the background music to adjust the volume of your audio. If you cannot hear sound, try the following:

  1) Check the “Hardware and Sound” folder in your computer’s “Control Panel” – check if you are muted, if the volume is set at a good level, and if your playback device is set to be the system’s “default”

  2) Close and restart the webinar

  3) Close and restart the webinar in a different browser (Internet Explorer vs. Google Chrome vs. Mozilla Firefox)

  4) Let us know if you need additional help by typing into the “Chat” box

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RGP of Toronto Network Webinar

Rules of Engagement: Essentials to Consider in a Patient Engagement Initiative

January 19 2017

Cathy Fooks, President and CEO
The Change Foundation
TODAY’S AGENDA

1) Brief overview of PATH and PANORAMA

2) Engagement Lessons from PATH and PANORAMA

3) Q&A
THE CHANGE FOUNDATION

• Established by the Ontario Hospital Association in 1995
• Charitable Foundation with an endowment of $65m
• An independent health policy think-tank that works to inform positive change in Ontario's health care system.
• Carrying out our mandate: Research, Policy Analysis, Care Delivery Re-design, Public Engagement
PATH PROJECT

- Partnership of 12 provider organizations with patients and family caregivers in the Northumberland Hills community.

- Branded as PATH: Partners Advancing Transitions in Health Care

- Original idea was to focus on transitions of care (primary care to hospital, hospital to home or LTC)

- Experience based co-design process with patients and caregivers changed the focus dramatically (yay)

- Two years of deep engagement with community changed local care as well as many other spinoffs

- Work has continued without Foundation $
PANORAMA

• 32 member advisory group to the Foundation

• No specific project but source of honesty about whether our work was patient and caregiver centered

• General advice on various issues we were grappling with:
  • Are system navigators a good idea? (maybe)
  • Should we pay patient and caregiver participants for their advice? (in some cases)
WHAT DID WE LEARN?

Will share our top 15 (couldn’t get it down to 10) lessons.

Some of this will seem like common sense. It is.

Overall message is be purposeful – do not engage because you are being forced to. Engage because you need and want to.

Guess what? Its really hard and really fun and really worth it.
Consider a range of engagement formats

A number of ways exist for patients and caregivers to help improve the quality of health care and the health care experience.
Choose the best timeframe for meaningful input

Some successful engagements last three to six months, others bring people together just once.

It’s a highly contextual assessment.
Consider partnering

By having more than one organization working with the same participants, you can “share the wealth” of wisdom and experience.
Recruit wisely

Aim for a mix of people who are new to public engagement and those who are experienced or even seen as champions in the role.

Pay attention to diversity in all forms.
Be clear about your purpose and objectives

From the start, give your participants clear understanding of the engagement’s purpose, objectives, conditions for success, and level of involvement.
6 Be clear about your scope of influence

Tell the participants the level of influence or authority your organization has to implement changes, and be clear about what your organization cannot do.
Develop a code of conduct together

Build solidarity and commitment by creating and agreeing on rules together.

GROUND RULES FOR DIALOGUE

- Express disagreement with ideas, not personalities
- We are all equal. Leave rank at the door
- Share airtime
- Listen respectfully, especially when you disagree. Acknowledge what you have heard the others
- Stay on topic. Connect to what others have said
- Look for common ground
- Understand & learn from each other
- Identify & test assumptions
8 Have an exit strategy

In the course of a long-term engagement, some people will leave. It may not be a good fit for them or they may have to leave because of changes in their circumstances.

Regardless, you need to know when the work is done or ensure it stays fresh if continuing.
Give participants the tools they need

Provide participants with accessible, relevant, and neutral resources and support, so they can build their knowledge and skills. This will also increase their confidence and capacity to engage.
10 Expect the unexpected...

And be open to it!
Give participants the recognition they deserve

Always acknowledge the contributions and impact of participants when reporting to the public and other audiences.
Commit to a feedback loop at the beginning, and follow through.

If you don’t implement their advice, tell them why.
13 Be prepared for lulls, and how to navigate them

If you’re planning an extended engagement, expect lulls in the activity and intensity and talk openly about why it happens and that it is expected.
Be aware and careful of people’s emotions

Sensitivity, empathy, and consideration will be needed if your discussions bring up sadness, grief, or anger.

Provide supports for participants but also for staff.
When things are coming to a close, act as a bridge for your participants if they are interested in contributing elsewhere.
A WORD ON PAYMENT/EXPENSES

• It goes without saying that expenses must be covered but there be ones you aren’t used to:

  ➢ Attendant services for someone a caregiver is caring for to enable the caregiver’s participation;
  ➢ Attendant care to accompany someone to participate in person;
  ➢ Child care;
  ➢ Animal sitting if there is an overnight required;
  ➢ Accessible transportation;
PARTICIPANT COMPENSATION

• Current practices vary.

• We created a framework available on our web site that provides a decision process to help you decide. (www.changefoundation.com)

• Based largely on the time commitment and intensity of contact required.

• Even if you decide no, need to demonstrate you have given it due consideration.
QUESTIONS?

For the Panorama Rules of Engagement report and resources please visit:

www.changefoundation.ca/panorama
Thank you for attending this webinar!

You will receive a quick evaluation survey by email – please share your suggestions and topics for future sessions.

A link to presentation slides and a recording will be provided after completing the evaluation.

Please save this date and join our next webinar on: 

**Wednesday, February 22 2017, at 12-1pm**

Hospice Palliative Care Ontario
Health Care Consent Advance Care Planning Community of Practice

“**Health Care Consent and Advance Care Planning in Ontario**”

If you have additional questions, contact [ken.wong@sunnybrook.ca](mailto:ken.wong@sunnybrook.ca)

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