

15 WAYS TO SUPPORT THE MEANINGFUL ENGAGEMENT OF CAREGIVERS, PATIENTS AND FAMILIES

The Rules of Engagement were designed as a set of simple guidelines to help health care organizations support the meaningful engagement of caregivers, patients, and families to create sustained and meaningful change across care settings.

There is growing recognition in Ontario about the importance of caregiver, patient and family engagement as a critical success factor for healthcare improvement. People with lived experience in the health care system have valuable expertise, wisdom and insights to offer. Evidence shows that when they are involved from the outset to drive change in health care, it can result in a better care experience and better health outcomes.

This resource provides an in-depth overview of the Rules of Engagement. A [one-page Rules of Engagement Summary](#) is also available.





15 WAYS TO MEANINGFULLY ENGAGE WITH CAREGIVERS, PATIENTS AND FAMILIES

1 Consider a range of engagement formats.

There are a number of ways for caregivers, patients and families to help improve the quality of health care and the health care experience. Depending on what your objectives are at different stages of your engagement work, you may want to use different approaches at different times. If you're unsure of the best approach for your engagement initiative, please refer to Appendix A that outlines a variety of engagement models.

2 Choose the best timeframe for meaningful input

The key is to choose the best duration and frequency of meetings for gathering meaningful input for your project, purpose, or initiative. Some successful engagements last three to six months, others bring people together just once. It's a highly individual assessment. For example, if an organization wanted input into a new strategic plan, participants might need considerable time to gain enough institutional background and knowledge to participate. Generally, factors to consider in shaping your engagement process include:

- its purpose,
- the resources and supports available,
- the anticipated level of commitment from participants,
- the complexity or specialized focus of the project or initiative,
- the urgency of the issue.

3 Consider partnering

Undertaking a patient/caregiver engagement exercise with another organization can have a range of benefits. By having more than one organization working with the same participants, you can "share the wealth" of wisdom and experience they bring. It's a more efficient use of each participant's time,

can lead to unexpected opportunities for collaboration between organizations, and can reduce resource intensity and costs for the organizations, especially in the case of face-to-face engagements.

4 Recruit wisely

Regardless of the length or complexity of your initiative, it is crucial that your participants be representative and engaged. Consider questions such as these when choosing your recruitment method and inclusion and exclusion criteria: Whose voices and experiences are most relevant to the conversation? Are both caregiver and patient perspectives important?

What issues will be discussed? And how? (e.g., through storytelling and discovery, or through broader, policy-based discussion?)

- The type and depth of your engagement will obviously help to determine your recruitment process.
- Ensure you recruit participants who reflect the diversity of the people your organization serves, and the larger community.
- Be aware that the patient experience may be quite different from the caregiver experience and bring different wisdom. You may want to recruit participants from an existing online forum (such forums have grown in Canada recently, in both the public and private sectors) and then bring them together in another setting. This could simplify the process, saving money or other resources. However, you should 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.

5 Be clear about your purpose and objectives

Often, engagements are too open-ended or have overly ambitious goals, especially at the outset and especially when the convener is new to engagement work. From the start,

give your participants as clear as possible an understanding of the engagement's purpose, objectives, conditions for success, and of the level of involvement you expect from them. Let them know that things may evolve (but not beyond their comfort level), and to expect the unexpected, as we discuss in No. 10. Some questions to consider, for your own clarity: How will the engagement advance your strategic focus and goals as the convening or host organization?

- What is the vision for the engagement and how does it align with or relate to your organizational vision and mandate?
- How will you communicate the vision to participants?
- Have conveners and key stakeholders agreed on a clear process by which the objectives and/or expectations can be expanded, reduced, or amended?
- If so, does the process give everyone—including participants—the opportunity to contribute and to decide on change?
- How will you seek participants' input into decisions, especially as the engagement evolves?
- Will the engagement connect to policy change, program design, service delivery, or a combination thereof? If so, how?
- Which decision-makers or organizations will be informed by the knowledge and perspectives gathered through this engagement? And for what purpose will they use it?

6 Be clear about the organization's scope of influence

Tell the participants what level of influence or authority your organization has to implement changes and be clear about the scope—and limits—of your organization's power from the start. Otherwise, you may set your participants up for disappointment. Be prepared to remind the group of your organization's scope a number of times, especially early on in the engagement process.

7 Develop a code of conduct together

Your engagement will need a code of acceptable conduct and it's important that you and the participants develop it together. Creating and agreeing on rules together, as part of the initial team-building process—rather than having them dictated by the host organization—builds solidarity and commitment. It also promises the best and most workable code of conduct for your specific project.

- The foundation of the code of conduct should be an understanding of the importance of the confidentiality and privacy of all of the participants, and committing to protecting it. The code should also set out other expectations for participation, including commitment to respectful communication, and the acceptable levels of contribution and attendance. You and the group should lay out a plan for addressing any participation problems in a fair, sensitive, and transparent way. As a starting point for building a code of conduct, refer to Ground Rules for Dialogue in Appendix B.

8 Have an exit strategy in place

It is important, to have an exit strategy in case you need one. In the course of a long-term engagement, it can be expected that some people will leave, or be asked to leave. The engagement may not be a good fit for them, but it's at least as likely they may have to leave because of personal or medical issues, or changes in their circumstances over time.

9 Give participants the tools they need

In this case, "tools" means knowledge. Provide them with accessible, relevant, and balanced resources and support, so they can build their knowledge and skills. This will also increase their confidence and capacity to engage.

- If you're seeking their input into policy or system change, you will need to frame issues in a way that is relevant to policy

and is also relevant to people's experience and responsive to their (probably diverse) learning needs. Creating resources for this task calls for skill and experience, and also merits careful attention. Allow for this in your schedule, budget and staffing.

10 Expect the unexpected...

And be open to it! As noted in No. 5, it's important in caregiver, patient and family engagement work to have clear objectives. However, because this is a dynamic process, it's important to expect and embrace new ideas and opportunities that may emerge. (If they do, you've struck gold!) We know of no easy way to achieve this balance between pursuing objectives and being open to new directions. Experience helps, as does the confidence experience can bring. Awareness of this delicate balancing act is a good start.

11 Give participants the recognition they deserve

Always acknowledge the contributions and impact of participants when reporting to the public and other audiences. Acknowledgment is a critical part of keeping "your end of the bargain"—not only at the final results stage of your project, but throughout.

- In some cases, recognition may also mean compensation. For compensation guidelines, please refer to The Change Foundation's [Should Money Come Into It?](#)

12 Report back

Commit to a feedback loop at the beginning, and follow through. After gaining information or advice from participants, tell or show them what you did, or didn't do, with it, and tell them why. This gives them a real-time view of the impact they're having. Reporting back also means telling them how you've acknowledged them in your activities or documents.

13 Be prepared for lulls, and how to navigate them

If you're planning an extended engagement, tell your participants to expect

lulls in the activity and intensity. For example, when the project moves from strategy to implementation, let participants know that their role may be put on hold, reduced, or shifted. Some may experience this as a loss; some may start to disengage. Advance notice is one way to reduce these problems. Also, keep communication open during lulls, and, if possible, offer relevant alternative activities.

14 Be aware—and careful—of people's emotions

Sensitivity, empathy, and consideration will obviously be needed if your discussions bring up sadness, grief, anger, or traumatic memories. You may want to go further and consider special training or support for staff and facilitators, and access to mental health supports for participants. Consider offering space for quiet rooms and telling participants, they are free to take breaks as needed during engagement activities.

- At the end of a long-term engagement, or even an intensive shorter-term one, some people may feel a strong sense of loss. This is most likely if they've developed friendships in the group, if they come from dispersed locations, or have found it very meaningful to be part of. Try to prepare for this. Consider gradually winding down activities, or look for ways your organization can help people stay in contact.

15 Carry it forward

When things are coming to a close, act as a bridge for your participants. They will have gained knowledge and awareness from the engagement, especially if it was extensive or long-term. Encourage them to join other groups or advisory boards. For those who show interest, you may want to provide suggestions or even contacts and introductions—a fitting last gesture for a successful patient/caregiver engagement.

APPENDIX A RESOURCES RELATED TO METHODS AND PRACTICES IN EFFECTIVE CAREGIVER, PATIENT AND FAMILY ENGAGEMENT

World Café

Participants gather around small “café” tables, discussing questions prepared in advance. Discussions are timed and participants split up and change tables with every round so everyone’s ideas blend and expand.

Participatory Consensus Conference Model

Consensus conferences are chaired meetings where members of the public come to decisions through discussion and consensus.

Open Space Technology

Open space events are large group sessions organized around a theme. Participants decide how to run the meeting and what to discuss.

Charrette

A charrette is multi-disciplinary workshop with the aim of developing a design or vision for a project or planning activity spread over multiples days.


Participedia – Strengthening democracy through shared knowledge

<http://participedia.net/> This website provides a large article and database to support evidence-based answers to the question about what kinds of participatory processes work best for what purposes and under what conditions.

The National Coalition for Dialogue and Deliberation

<http://ncdd.org/>
The National Coalition for Dialogue & Deliberation is a network of thousands of innovators who bring people together across divides to tackle today’s toughest challenges.

APPENDIX B 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 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



ADDITIONAL RESOURCES:

<http://www.theworldcafe.com/>
<http://www.theworldcafecommunity.org/>
<http://ncdd.org/rc/item/355>
<http://www.kstoolkit.org/The+World+Cafe>
http://archive.unu.edu/hq/library/Collection/PDF_files/CRIS/PMT.pdf
<http://ncdd.org/rc/item/1492>
http://archive.unu.edu/hq/library/Collection/PDF_files/CRIS/PMT.pdf
www.openspaceworld.com
<http://ncdd.org/rc/item/1574>
<http://www.chriscorrigan.com/parkinglot/open-space-resources/>
<http://charretteinstitute.org/blog/nci-charrettes-collaborative-design-thinking/#more-1597>
http://www.tndtownpaper.com/what_is_charrette.htm