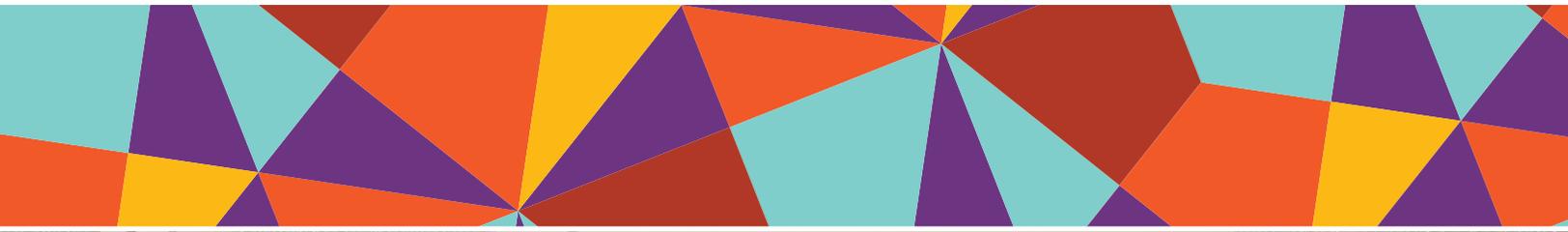# THE **CHANGE** FOUNDATION

ENGAGE, EXPLORE, EVOLVE

RULES OF ENGAGEMENT: LESSONS FROM PANORAMA

panorama

RULES OF ENGAGEMENT: LESSONS FROM PANORAMA

PROJECT BACKGROUND

Patient Engagement. It's no longer a buzzword in Ontario's health care sector. It's an expectation —and for good reason. The literature shows when patients and families are involved from the outset to drive change in health care, patient experience and satisfaction rates go up and costs often go down.

However, meaningful patient engagement isn't necessarily easy, and is often met with organizational and systemic barriers.

Patient engagement was the focus of The Change Foundation's 2010-2015 Strategic Plan – *Hearing the Stories, Changing the Story*. Our Strategic Plan committed us to focusing on patient engagement and improving the patient experience. And we knew we needed to walk the walk by creating a way to directly work with, listen to, and learn from patients.

That was the reason behind the creation of our PANORAMA panel, formed in 2012, that brought together 31 people from across Ontario. The panellists didn't necessarily have a lot in common, except that they all had frequent, ongoing contact with the health system; they had at least one chronic condition or were caring for someone who did. For two-and-a-half years, the panellists drew on their own experiences, good, bad, and in-between, to help improve the patient and caregiver experience for others. Their observations, ideas, and reflections shaped our understanding and directly contributed to and informed our work in the following ways:

- Individual panellists joined the Foundation in a wide range of meetings and conferences, with groups that include: the Association of Family Health Teams of Ontario, Kingston General Hospital, Patients Canada, the Ontario Hospital Association, Health Quality Ontario, and various Local Health Integration Networks.

- Their insights changed our perspective on the usefulness of patient navigators, which changed our recommendations outlined in *Health System Navigators: Band-Aid or Cure?*. We assumed that a navigator would be helpful, but the PANORAMA panellists said they did not want another person involved in managing their care, but rather they preferred that an existing care team member manage their care.

- PANORAMA actively collaborated and advised on the development of our groundbreaking Partners Advancing Transitions in Healthcare(PATH) project including the PATHWay to Aging Well portal and hand-held technology.

- The Change Foundation's *Should Money Come Into It?* compensation framework for patient volunteers was shaped by input from the PANORAMA panel.

- In developing our new Strategic Plan, the panel was one of our sounding boards. They provided words of wisdom about the language we use for caregivers, and reminded us not to lose sight of diversity—the patient and caregiver experience are unique, but intertwined.

PANORAMA was a ground-breaking project for Ontario, and along with the PATH project, served as an incredible learning and growing opportunity for The Change Foundation.

As a thought leader in health care policy, we want to share the knowledge gained through our involvement with PANORAMA, and other engagement activities. We believe that others can benefit from what we learned and use it to build their own work.
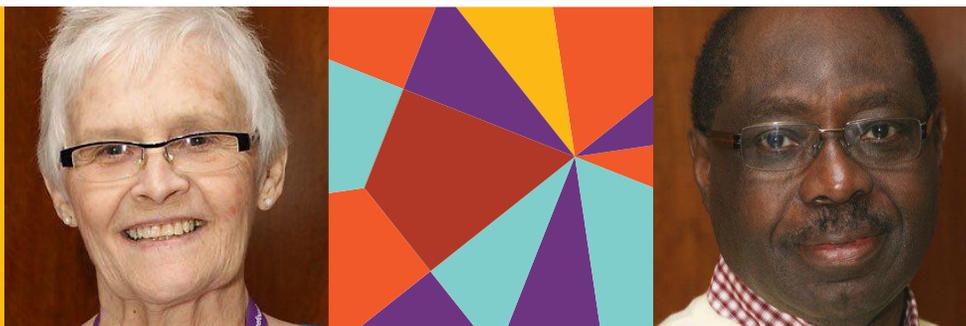
THE CHANGE FOUNDATION'S TOP RECOMMENDATIONS AND TIPS FOR PATIENT ENGAGEMENT

The recommendations below are in overlapping but generally chronological order.

1. **Consider a range of engagement formats**
   There are a number of ways for patients and caregivers 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. In it you'll find engagement processes such as the open space planning method[1], consensus conferences[2] and the World Café[3], along with links to additional resources.

2. **Choose the best timeframe for meaningful input**
   The PANORAMA panel met for two-and-a-half years, but 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.

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

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

[3]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.

3. **Consider partnering**

   Undertaking a patient 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?

   • 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.

   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.

    For example, the role of The Change Foundation is to influence. We create projects that produce evidence and examples, but we can't control health care delivery, and we don't write the policy that drives it.

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 PANORAMA's Ground Rules for Dialogue in Appendix B.

8. **Have an exit strategy in place**
    With PANORAMA we were fortunate: almost all of the panellists contributed appropriately and stuck to their commitment, attending all, or most of, the sessions. It is important, though, 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. 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 laypeople'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 patient 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. For example, in all the recommendations and activities influenced by PANORAMA, we explicitly highlighted what the panellists had said and how it changed our thinking. Such acknowledgement 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 Foundation's *Should Money Come Into It?* report.

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.

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, as many of our PANORAMA panellists have done. For those who show interest, you may want to provide suggestions or even contacts and introductions—a fitting last gesture for a successful patient engagement.

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- Jacquie Dale (One World Inc.)

ABOUT THE CHANGE FOUNDATION

An independent health policy think tank, The Change Foundation is changing the debate, practice and experience in Ontario health care, prompting system-wide improvements for patients and family caregivers. The Foundation engages the stewards, stakeholders, and users of Ontario health care, advising, supporting, and challenging them to work together on shared goals: better health and quality of care; better patient and caregiver experience and engagement; better value for money.

APPENDIX A

METHODS AND PRACTICES IN EFFECTIVE PATIENT AND CAREGIVER ENGAGEMENT

Participatory Consensus Conference Model
A consensus conference is a public enquiry centred on a group of 10 to 30 randomly selected citizens who are charged with the assessment of a controversial topic. Members (sometimes referred to as a Panel though the model is quite different from the PANORAMA Panel model) participate in two preparatory weekends and are provided with credible and balanced material to gain a basic understanding of the issue at hand. Citizens then participate in a three to four day conference. Over the duration of the conference, the citizens interact with experts, forming iterative questions based on their learning and deliberations. Citizens then prepare a final document containing their views, opinions, stances, and recommendations for the issue. On the final day of the conference, the citizens discuss their final document with policy- and decision-makers. The goal of these participatory consensus conferences is to broaden the debate on a given issue, bringing citizens' values, considered opinions, and points of view to arrive at a consensus opinion, to either inform or decide on upon a policy decision.

The model of participatory consensus conferences (often referred to as 'the Danish model') originated in Denmark in the 1980s and is one of the earliest attempts by policymakers to include the lay publics' opinions in their decision-making through public engagement. Variations of this model have been used throughout OECD countries, including Canadian Blood Services who used it to deliberate on a risk based decision-making framework for blood safety. This model is best used when there is a need to bring citizens' collective considered views and values to bear on a policy decision that needs to be made or important inputs needed for decision-making.

Links to Additional Resources:

http://people.ucalgary.ca/~pubconf/Education/grundahl.htm

http://ncdd.org/rc/item/1492

http://www.loka.org/trackingconsensus.html

http://estframe.net/ethical_bio_ta_tools_project/content_2/text_2c81d261-b7a8-43e8-8f1e-d724b43e2ba3/1346076808107/et4_manual_cc_binnenwerk_40p.pdf

http://www.co-intelligence.org/P-ConsensusConference3.html

http://archive.unu.edu/hq/library/Collection/PDF_files/CRIS/PMT.pdf

Consensus Conference

Participatory consensus conferences

https://en.wikipedia.org/wiki/Consensus_conferences - cite_note-Scheufele-1

Open Space Technology

Created by Harrison Owen, Open Space is a highly participative planning method in which participants self-organize around an agenda they create and manage. It is important to note that Harrison Owen never trademarked or patented or certified "open space" in any way. He always claimed to have discovered, rather than invented, it. He said it could be practiced freely by anyone with a good head and good heart. From the beginning, he said only that those who used the approach and found it valuable, should share their stories and learnings as freely, as well.

With Open Space there is no structured agenda at the start of the Open Space event. Participants create their own agenda by choosing topics, related to the focus question, about which they feel some passion and responsibility. The process begins with themes, usually in the form of a question for the group to address, but no particular outcome or solution is assumed in advance. These themes can be identified by citizens or conveners or through a joint identification method. Passion and responsibility are the key fundamentals of Open Space. Without passion, no one feels motivated. Without responsibility, nothing gets done. For these reasons, and in keeping with self-management principles, participation in an Open Space event should always be voluntary.

During an Open Space event, participants are invited to come to the center of the circle, write down their topic/issue of interest related to the focus question on a note card, announce it to the group and post it on a schedule of discussion groups. The issues/topics become the basis for discussion groups around which participants self-select. No one can complain about a particular issue not getting discussed because everyone has equal opportunity to submit topics. If a topic is not raised, then no one felt enough passion about it to take responsibility for hosting a discussion group.

Participants are responsible for their own learning and therefore to move to a different discussion group any time they are in a situation where they are neither learning nor contributing. Rather than remain in a situation where their time is being wasted, participants are encouraged to get up and move to a group that meets their needs.

The process is particularly effective at uniting diverse groups around a complex and contentious issue that requires attention and new thinking.

Links to Additional Resources:

www.openspaceworld.com

http://www.openspaceworld.net/

http://openspaceworld.org/wp2/

http://www.openspaceworld.com/users_guide.htm

http://www.openspaceworld.org/cgi/netwiki.cgi

http://www.openspacecanada.org/

http://ncdd.org/rc/item/1574

http://www.chriscorrigan.com/parkinglot/planning-an-open-space-technology-meeting/

http://www.chriscorrigan.com/parkinglot/open-space-resources/

http://www.vaughanconsulting.com/openspace.html

http://www.michaelherman.com/cgi/wiki.cgi?OpenSpaceTechnology/invitingorg/index.html

http://www.dailykos.com/story/2011/05/09/974520/-Participatory-Models-Open-Space-Technology#

World Café
Originating in the United States, the World Café is a creative process for facilitating collaborative dialogue and the sharing of knowledge and ideas to create a living network of conversation and action. In this process, a café ambiance is created in which participants discuss a question or issue in small groups around the café tables for approximately 20-30 minutes. At regular intervals the participants move to a new table. One table host remains and summarizes the previous conversation to the new table guests. Thus the proceeding conversations are cross-fertilized with the ideas generated in former conversations with other participants. At the end of the process the main ideas are summarized in a plenary session where key ideas and conclusions are established. Another option is to have participants use sticky notes to write down their ideas, and then to have each table select their top three to five ideas to go to an ideas wall for clustering into themes. At the close of the world café a dotmocracy exercise (alternatively this can be done with electronic keypads) is used for participants to select their top ideas (usually no more than 10).
This helps distill what are the group's priority items.

This process works best with pre-assigned table hosts who have been trained or oriented to their role. Likewise having trained individuals to do the clustering and synthesis is also highly recommended. Variations of the world café process are used within other participatory processes.

Links to 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

The World Cafe

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. At the core of the process is a design team, typically a multidisciplinary team of professionals. Their job is to take what they are hearing from various publics (could be caregivers and patients) and translate it into a form that could be implemented (i.e. design, program or policy or whatever the topic of the charrette may be). Participants are specifically invited to attend two public meetings, several days apart, but they are also invited to drop in at a charrette studio, where the design team is working to translate what they hear from the public into implementable designs, plans or programs.

The first step is for the design team to set up the charrette studio, the physical space in which the design team will work and which will be a constant open house for anyone who wants to drop in to discuss the topic of the charrette. Because it is both workspace and discussion space, the design team does its work in a highly visual manner, posted on walls, so that the public can see what they are doing.

The first public meeting is a kickoff meeting followed by a hands on workshops. The next day, the design team begins to develop alternative designs, plans or programs based on what they heard in the workshop. All participants are invited to drop in at the charrette studio to discuss the issue further or react the materials the design team is developing. The design team may also out into the community to conduct interviews with key stakeholders. For several days, the design team keeps refining the plans until it has a proposal to present to the community. There is then a public meeting during which the proposal is presented to the public for comment or approval.

Over the next several weeks, the design team continues to refine the proposal and may continue to interview stakeholders. Approximately one month after the charrette, there is a final public meeting to review the documents prepared by the design team.

One of the keys to the success of a charrette is a well-planned public outreach effort prior to the charrette to solicit and encourage interest and involvement of whichever communities or groups are needed for the charrette. The other key is the skill of the design team. The team must have the ability to take what they hear from the public, providing sufficient detail so that it is implementable, yet keeping their own ideas and biases out of the process sufficiently so that the final product is recognizable to the public as a translation of what they told the design team. Charrettes have been used in different domains, and while they are most known for developing community plans, land use, architectural choices (landscape, industrial and public), they have also been used for social and health planning.

Links to additional resources:

http://charretteinstitute.org/blog/nci-charrettes-collaborative-design-thinking/#more-1597

Charrette

http://www.tndtownpaper.com/what_is_charrette.htm

ADDITIONAL RESOURCES ON PARTICIPATORY PRACTICES:

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. It is intended to be of use to social scientists, policy analysts, democratic theorists and scholars, practitioners, government officials, activists and journalists. It includes over 99 items on methods, 496 cases, and 368 items on organizations involved in this space. The cases include information on: methods, facilitation, type (online, F2F, both), type of interaction, decision methods, target audiences, and method of communication with audience. Participedia recently received an infusion of funds to further develop its website.

Some of the methods of note included on the website are:

- 21st Century Town Meeting
- Agora, global parties
- Bungeni Parliamentary and Legislative Information System
- Cabildo Abierto
- Charrette
- Choicework Dialogue
- Citizen Advisory Board
- Citizen Conferences
- Citizen Councilor Network
- Citizen Dialogue
- Citizens' Initiative Review
- Citizens' Jury
- Community-based participatory research
- ConsiderIt
- Conversation Cafes
- Crowdsourcing
- Deebase - e-deliberation made easy
- Delegated Voting
- Deliberative Democracy
- Deliberative Democracy and Citizens' Juries
- Deliberative Polling
- Democs
- Direct Representation (Minimal Coleman)
- Dynamic Facilitation
- e-Deliberation™
- Electoral District Forum
- Evaluating the efficiency of participation
- Guide to Evaluating Participatory Processes
- Initiative Process
- National Issues Forum
- Online deliberation
- Participatory Budgeting
- Pop-up Democracy
- Practical Democracy
- The Occupy Movement's use of social media as an organizing method
- Wikivote
- Workers' Council

This link is to case examples of patient engagement and includes over 30 cases worwide.
http://participedia.net/en/search?search_api_views_fulltext=patients

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. NCDD serves as a gathering place, a resource clearinghouse, a news source, and a facilitative leader for this extraordinary community.

Over 180 tools and methods used for dialogue and deliberation are listed on this website here:
http://ncdd.org/rc/item/category/participatory-practices

CPRN – Handbook on Citizen Engagement: Beyond Consultation
http://www.cprn.org/documents/49583_EN.pdf

Centre for Public Involvement (Edmonton Alberta) http://centreforpublicinvolvement.com/

APPENDIX B

GROUND RULES FOR DIALOGUE

THE CHANGE FOUNDATION

Express disagreement with ideas not personalities

Share airtime

Stay on topic—connect to what others have said

Understand & learn from each other

We are all equal. Leave rank at the door

Listen respectfully especially when you disagree. Acknowledge you have heard the others

Look for common ground

Identify & test assumptions

changefoundation.ca