

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 public's 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 a multi-disciplinary workshop with the aim of developing a design or vision for a project or planning activity spread over multiple 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 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 to the materials the design team is developing. The design team may also go 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 worldwide.
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/>