

Selecting the Right Collaboration Platform for Public Engagement in Health

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Health research and service provision are two of the most important and costly components of modern life. But they are fraught with profound ethical and priority setting issues which complicate decisions about what research and services are in the overall public good. It is critical that citizens be allowed to participate in these decisions.

Two leading health organizations in Canada, The Joint Centre for Bioethics, University of Toronto and the Centre for Global eHealth Innovation, University Health Network, decided to implement a state-of-the-art Information and Communication Technology (ICT) platform to facilitate citizen engagement in the Canadian health sector. With financial support from several government agencies, we set about analyzing the functions and tools available to support public engagement in the broad arena of health research, decision making and service provision.

The Rationale for the Platform

The platform had to support the three principal objectives of public engagement:

1. **Decision making**, including participation in planning, resource allocation, and policy development.
2. **Action**, meaning citizen participation in the implementation of programs, for example, direct involvement in gathering data and evidence; participating in advocacy efforts, surveillance and implementation of public health campaigns.
3. **Accountability**, allowing the public to monitor and evaluate public or private sector compliance with decisions taken.

For each one of these objectives, engagement can be measured along a continuum that has been loosely defined as having five levels:



The collaboration platform had to support all five levels of engagement. This meant that the technology had to enable the following capabilities:

- Sharing information in electronic data and audiovisual formats
- Allowing citizens to gather and submit research or surveillance data in a variety of formats from structured data to open-ended or unstructured information.
- Bringing people together to support dialogue, decision making, and different sorts of group processes, in both real-time and asynchronous settings.
- Support for groups of varying sizes
- Accessibility to a wide range of people with varying levels of experience with and access to technology.

Selecting the technology

For each activity the platform had to support, we developed lists of the required functions; created online wiki-based surveys shared with all members of the project team; and used their input to help select among the thousands of tools available in the marketplace. We chose to purchase a suite of hardware and software tools from different providers rather than an enterprise solution from one provider. We also

avored, whenever possible, open-source options but were not limited to them. The result is a collaboration technology platform that includes:

- A content management system (CMS) and web casting tools to enable information sharing (Jahia and ePresence respectively).
- Mobile data collection devices such as PDAs, kiosks, and web-based survey tools to engage citizens in gathering data.
- Webinar and decision support software for collaboration and group dialogue (Breeze and FacilitatePro).
- Physical facilities for face-to-face meetings enabled with full multimedia and computer capacity (including the infrastructure to support over 100 wireless devices at a time, videoconferencing, multimedia production and post-production, and electronic whiteboards)

Results from Implementing the Platform

The platform has been in place for just over a year now and has been used in a variety of innovative research and public action contexts.

- A 21st century town hall to validate a decision-making tool related to end-of-life decisions.
- Town hall meetings where health professionals and consumers discussed priority setting for distribution of scarce vaccines during a pandemic
- A major public education and information initiative around innovations in agricultural and food research related to healthy eating and lifestyles
- A peer-review process that feeds into decisions about publishing, membership, and grants integral to the knowledge transfer process that underlines all health research.
- Webcasts to engage secondary school youth in discussions about public health goals
- International discussion forums on various public health issues
- Virtual focus groups with health providers to develop a program to increase understanding of and participation in cancer clinical trials

In short, our preliminary experience has led us to conclude that the ICT platform has enhanced the capacity for meaningful public engagement in decisions and services related to human health. And, ICTs greatly increase the ability to easily document and evaluate such public engagement for accountability and research purposes. But this experience also brought home to us that that clarity of purpose and choosing the proper tool for each activity is also fundamental, and that facilitators play an important role in bringing the platform to life.

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