Community Engagement via a Virtual Patient Focus Group

The concept of community engagement is neither new nor provocative [i]. Since the mid seventies, considerable work has been done to understand the different typologies and characteristics of various engagement models. In this regard, Sherry Arnstein's 1969 analysis is still relevant even in 2007[ii]. Specifically Arnstein described different degrees and levels of involvement where the first level aims are to educate, inform or communicate information to a particular stakeholder group.[iii] The second level of involvement or public consultation refers to a degree of involvement where the goal is to promote the exchange of information between the public and the consulting organization[iv]. The highest level of engagement, described as public participation, implies a participative type of involvement where partnership, power sharing and decision making go hand-in-hand.[v]

The strategy of using community feedback to advance organizational development or assist an organization in its change agenda is also well established and often used.[vi] The pressure felt by healthcare organizations to engage with its stakeholders' as part of their accountability agenda or their patient safety agenda is also not novel.[vii] Perhaps what is new is the modus operandi recently used by the University Health Network (UHN) to engage in a dialogue with its patients by the use of a web-based communication in order to create a standing virtual focus group.

The University Health Network (UHN) is a multi-site academic healthcare system situated in Toronto, Canada. UHN has demonstrated leadership in a variety of clinical, research and educative areas. The last five to ten years has seen a substantial commitment to the development and use of sophisticated information technology strategies. Particular excellence has been acknowledged in the development of the electronic health record, the automated medication ordering record/ medication administration record system and various elearning strategies.

Patient feedback has been sought and used in a meaningful way since 1993 via the establishment of a Patient Relations (Ombudsman) department and the use of corporate-wide mail out surveys (1994).

The notion of using the internet to engage in an ongoing dialogue with past or current patients and family members regarding their experiences at UHN arose in 2006 in response to an off-hand discussion around a specific issue where the question, "what do patients want?" was answered with the simple response, "let's ask them, I'll send them an email".[viii] And with this, a strategy was designed where patients who have communicated with the Ombudsman's office have been enrolled into a focus group. The major selling point to patients was that this gave them an opportunity to offer commentary, opinion and feedback on specific organizational issues. Every four to six weeks, various departments about specific and pressing organizational issues developed a set of questions. Responses came via email to an internal moderator. Summaries of all comments are looped back to the focus group. Patient opinions were formally presented to the originating department and to senior management for consideration. As of the onset of 2007, the focus group had 180 active participants and further growth was anticipated. The development of more sophisticated strategies, such as organized bulletin boards and chat room formats were being considered.

There are several positive aspects to a virtual focus group. First of all, this strategy leverages and advances an organization's established and strategic engagement plan. The low cost along with receiving the responses in real time, make it an extremely attractive and dynamic strategy. Email

technology has offered a level of intimacy and vitality that informs the sense that the organization is really listening. By recognizing the pervasive and growing use of personal computers across all demographic groups, the virtual focus group allows members to respond to questions and engage in a dialogue with the 'hospital' when it is convenient for them. The feedback received via this strategy is extremely rich in a qualitative sense as well as quantitatively.

Some challenges also exist. From a purely statistical or scientific perspective, there is a negative perception that the feedback is 'soft data' or 'patient opinions' and that this type of feedback is less worthy, accurate or compelling than other forms of information gathering. The virtual group communicates via an internal moderator in order to protect patient confidentiality and as a result the vitality and dynamism of face-to-face contact within a group or group membership is lost.

Over time, the virtual patient focus group will evolve into other unforeseen ways however the use of web based email has been an excellent and effective tool for patient engagement, involvement and consultation.

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ii   Arnstein, S.R. A Ladder of Citizen Participation. Journal of the American Institute of Planners, 35:216-223, 1969.

iii   Simces, Sena and Associates. Exploring the Link Between Public Involvement/ Citizen Engagement and Quality Health Care. A review and analysis of the current literature. Heath Canada, Health Human Resources Strategies Division, Ottawa, May 27, 2003.

iv   Ibid

v   Ibid

vi   Bate, Paul. Changing the culture of a hospital from hierarchy to networked community. Public Administration Vol. 78 No.3, 2000 (485-512). Blackwell Publishers Ltd.

vii   Ament, Lucy. MHA is helping hospitals to better understand their communities' needs. American Hospital Association News. November 27, 2006 (7).

viii   Rogers, Sharon. Management Meeting. 2006