ETHICS CASE

Should Health Care Organizations Use Information Gleaned from Organization-Sponsored Patient Support Groups in Strategic Planning?
Commentary by Priya Nambisan, PhD

Abstract

Online forums and partnerships with patients have several benefits, such as the creation of new products and services. However, as with any such initiatives, there are risks as well as benefits. Through analysis of a case of misinformation being spread through a health care provider-sponsored online support group for patients dealing with obesity, this article outlines best practices and strategies to deploy in such organization-sponsored patient support groups. These strategies would enable organizations and patients to use such forums to the fullest extent while preventing or managing their potential risks as best as possible.

Case

In an effort to help patients become more proactive managers of their own care, the National Star Health Network has asked Dr. Smith, an advocate for how online support groups can help patients, to lead the development of a National Star-sponsored program that would help patients in its network form online support groups, which enable sharing of information, stories, questions, or concerns. It's also hoped that the organization could gain important insights from what patients share in these online forums, such that the organization could develop services that are more responsive to patients' concerns.

Dr. Smith's team has recently initiated an online support group for patients who are obese. She hopes that this online group will not only be a source of empowerment for patients but also help the organization reap the benefit of patients' input in its ongoing strategic planning efforts to improve health outcomes for patients with obesity. When asked why they join the online group, patients state that they hope to support one another and also hope to offer suggestions to the network about how to be more responsive to health needs of obese patients in the community. Participation in the online support group is not anonymous, but participants can use aliases. Participants must check a box stating that they agree to share only information that is "true, to the best of my knowledge."

One participant shares that she lost weight by using a supposedly FDA-approved weight-loss assist device. "To use it," she explains to the group, "You just eat and then drain ingested but still undigested content from your stomach before you absorb the calories." This participant's experience generated a lot of excitement among other participants, so she shared the manufacturer's website for the device. Soon, other participants began to ask their physicians about it.

Dr. Ngwar is an internal medicine physician with National Star Health Network who has numerous patients with obesity who have been asking him about this device over the last few weeks. He calls Dr. Smith to explain his concerns. "Several colleagues and I have been getting pressure from our patients to insert this device in their stomachs. Some of these patients are refusing to try other weight loss methods, claiming that they've learned on the internet that other interventions are pointless. When we ask our patients how they learned about this device, they tell me that it's from the online forum that we sponsor. Is this true?"

Dr. Smith admits that the forum could certainly be a source of misinformation and clarifies that there are currently no clinicians or patient educators staffing the forum to respond to participants who are not well informed or who appear to be exaggerating alleged successes of a particular solution. Dr. Ngwar continues, "We need to do something about this. Patients are threatening to find other physicians willing to insert this device if we don't. I know that sponsoring these patient groups is part of the network's strategic plan to obtain patients' input about the services we offer, but this is just physician-assisted bulimia. I don't know a physician who would recommend this for a patient, and I don't know anyone in health care who endorses the use of this devise. Are we seriously considering offering this to patients?"

Commentary

Offering an online patient forum is perhaps one of the most important patient-centered initiatives a health care organization (HCO) can pursue. Studies indicate that such online patient forums can serve as a powerful vehicle for (a) knowledge creation and utilization [1, 2], (b) disseminating information to the patient community [3], (c) creating new products and services in partnership with patients (i.e., value co-creation) [2], (d) providing empathic support to patients [4], and (e) enhancing the image of the sponsoring organization [5].

As with any other organizational initiative, however, there are also some potential risks. For example, poor management of an online patient forum is likely to lead to patient dissatisfaction and frustration, dissemination of incorrect information and ensuing liability issues, improper patient expectations, and so on. Thus HCOs must carefully manage their online patient forums to maximize the benefits and minimize the associated risks. However, to do so requires developing a deeper understanding of what

goes on in such online patient forums. Who are the people participating? Why are they participating? What kind of conversations are going on? And, importantly, how and when do the patients benefit from these conversations in the online forum? This case analysis will put forth strategies to maximize benefits and minimize risks of online patient forums.

Preventing and Managing the Spread of Misinformation through Online Patient Forums
One potential risk associated with online patient forums is for the forum to become a conduit for misinformation, as evidenced in this case study. Misinformation on online forums, blogs, websites, and social networking sites is likely to be a serious threat to patient well-being as well as to the patient-clinician relationship, with much misinformation (e.g., linking vaccinations and autism) being spread through [social media sites](#) such as Facebook and Twitter [3, 6]. Although in certain instances, such misinformation sharing could be intentional (e.g., due to paid promotion of specific products), in other instances, it could be unintentional, as patients might truly believe that they are sharing valid information that would be of benefit to others. The latter scenario is particularly true in patient forums where there are discussions of alternative treatments, some clinically proven and some not. Patients who do not have the requisite knowledge to know the difference could innocently share misinformation.

In the National Star Health Network, a patient posts information regarding a supposedly FDA-approved weight loss intervention on an online patient support forum set up by the HCO. Although no clinician or patient educator monitors the forum, it should be noted that misinformation about weight loss shortcuts is available everywhere. Furthermore, one could argue that the patients in the forum who were excited about the device were likely susceptible to misinformation about weight loss shortcuts whether acquired from the forum or another source. However, in this case scenario, the discussion in the forum has clearly extended beyond the online community to Dr. Ngwar's office and his interactions with patients, as some of these patients want this supposedly FDA-approved weight loss device to be inserted in their stomachs. As such, it has become imperative for the National Star Health Network to adopt appropriate measures to minimize the potential negative effects of the sharing of misinformation on the online patient forum without curtailing the free flow of information and the ensuing benefits to patients. Below I suggest some approaches by which health care providers like National Star Health Network and health care professionals like Dr. Ngwar can address this situation at multiple levels and in multiple settings.

At the point of contact with the clinician. Each clinician-patient interaction is an opportunity to discuss and clarify misinformation. However, it is important for health care professionals to be the "guide on the side" rather than the "sage on the stage" [7]. In other words, they should be nonjudgmental and focus on facilitating patient learning through a more participatory model of patient care instead of relying on the traditional

paternalistic model [8, 9]. Even educated smart people can fall for misinformation. It is important to allow patients to reach the right decision themselves. Studies have shown, for example, that decision aids to increase patient involvement in decision making improve patients' understanding of the possible benefits and harms of treatment [10, 11]. The goal of patient participation in decision making can also be achieved by asking questions such as "do you think it is the right decision?," "do you know of the side effects or long-term effects of this surgery?," and so on. In the current case scenario, Dr. Ngwar should not only use decision aids but also provide supplemental information (e.g., on the side effects, poor quality of life, and other long-term issues that could potentially arise with this surgery), possibly through an interactive computer game or a visual simulation. One should recognize, however, that many of the patients who are asking their physicians about the device may be tired of trying "healthy options" and thus not be readily persuaded by the evidence. In such situations, it would be more effective if health care professionals could help patients to recognize the factors that are driving them towards potentially bad decisions and enhance their ability to distinguish misinformation from correct information to prevent their making bad decisions in the future. Training for health care professionals would go a long way in helping to realize this objective. Nevertheless, there are strategies, practices, and policies that HCOs such as the National Star Health Network could adopt now to help their clinicians manage misinformation.

At the organizational level. HCOs can adopt clear-cut policies on how to deal with patients who submit misinformation (to their physician or to online forums). Studies indicate that such situations require an effective communication strategy and often the development of a new set of communication skills for health care professionals [12, 13]. It is advisable not to immediately dismiss the information relayed by patients, as patients could put forward potentially useful information [12]. Instead, when seeing patients or monitoring an online forum, it is better to ask for time to collect additional information on a given issue [12] and then promptly get back to patients with information that is relevant and helpful for them to make an informed choice. This approach not only helps the patient to make an informed decision but also demonstrates to the patient that the information he or she provided is taken seriously by the clinician. More generally, validating patients' efforts to seek health information on the internet has been shown to result in improved patient satisfaction and patient-clinician trust [14]. Another approach to dealing with misinformation is to redesign the patient-clinician relationship to suit the organization by choosing one (or a combination) of the following models as a long-term strategy: a professional-centered model, wherein "expert" opinion is relayed to the patient; a patient-centered model, wherein both the health care professional and the patient together evaluate the new information; or a guidance model, wherein the clinician accepts patients' need for new information and seeks out and shares such information with patients in order to guide them [13].

The above strategies will be beneficial in the short-term (such as in helping Dr. Ngwar address his patients' concerns); it is equally important to simultaneously deploy forum-level policies and strategies to address broader issues that arise about the purpose and organization of such online patient support groups.

Effective Models for Using an Online Forum to Its Maximum Potential
An important and broader question posed by National Star Health Network's patient forum in this case concerns how health care organizations can glean useful information for value creation from such organization-sponsored online patient support groups. Online forums provide an excellent venue for HCOs to "listen" to their patients by providing a written text of patient conversations that can be analyzed. Organizations could also take an active approach to gleaning useful information from the forum by partnering with forum members to create new knowledge. Nambisan and Nambisan [2] suggest four models of value co-creation with patients in online forums: the *support-group model*, the *diffusion model*, the *open-source model*, the *diffusion model*, and the *partnership model*. These models are based on two dimensions: the nature of leadership (is the forum organization-led or patient-led?) and the nature of knowledge activity (does it involve new knowledge creation or knowledge sharing?).

Support-group model. The most passive strategy would be one in which the organization takes a completely hands-off approach and leaves patients in the forum to interact with one another in hopes that they will be able to derive some value out of it by sharing information. This approach seems to have informed the National Star Health Network's online forum as described in this case study. Such online support groups have been found to provide empathic support to patients [5] that in turn could lead to positive health outcomes. However, the disadvantages include the potential for patients' sharing inappropriate information or misinformation and the HCO's inability to manage the associated risks. Many HCOs adopt this approach since it calls for very minimal resource commitments on their part [4]. Indeed, support group models have been found to function as a cost-effective auxiliary service that, in the long term, could potentially improve patients' perceptions regarding the organization and its services [4, 5].

Diffusion model. HCOs can also take an active approach to knowledge sharing or diffusion [2]. For example, in the case of the National Star Health Network, the HCO can provide new information to patients and thus keep them up-to-date on recent developments in obesity and associated treatment options or in healthy living. HCOs could provide educational materials (e.g., through its website) to help patients better evaluate information (e.g., related to varied weight loss remedies) they acquire from the online forum or the internet. Importantly, this model also allows the HCO to diffuse information on new health care services through the online forum.

Open-source model. Another relatively passive approach from the clinician's perspective—the open-source model—delegates to patients the generation of new ideas related to improving existing health services that could benefit them as well as the organization. The National Star Health Network's online forum reflects this approach insofar as patients shared information about a new treatment with their physicians. As in this case, the approach can lead to challenging situations in which some ideas might be deemed clinically unsafe or undesirable by the HCO. An appropriate strategy would be for the HCO to filter the ideas and reward those that are deemed most useful or innovative by instituting idea competitions or contests. For example, in this case scenario, Dr. Smith could collect all such patient-contributed ideas from the online forum and present them to an internal team who could then evaluate which of those ideas are worthy of further consideration.

Partnership model. A more active approach is the partnership model, wherein the organization takes the leadership role and specifies very clearly how and for what purpose it wants to partner with patients in creating new knowledge. Examples of such active partnership with patients include clinical trials, in which patients are called on to report side effects of certain treatments or drugs, give feedback on new health care services, and so on [2]. The data obtained from these activities in the online forums could then be analyzed and used for making strategic decisions within the organization regarding treatment options, prescription drugs, or developing new patient services [1].

Conclusion

Overall, these models of value co-creation offer a portfolio of choices or options for HCOs—each with its own advantages and disadvantages—to actively engage with their patients in developing and sharing information about new programs and offerings. Clearly, Dr. Smith and her team could provide feedback on the health-related information that patients bring to the forum or their clinician to address patients' insistence on receiving clinically unproven treatments that they heard about online. However, what is also evident from this case study is the need for the National Star Health Network to adopt a more active model for value co-creation by using the online forum to glean and share valuable information that would eventually benefit the National Star Health Network, its clinicians, and, importantly, its patients.

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