

# Crowdsourcing and patient engagement in research

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**H**ealth care providers, funders, and decision makers generally agree that getting input from people who use the health care system helps ensure its effectiveness. The more input, the better. As a result, patient representatives now sit on hospital boards, advisory groups, and health care panels. Health care research should also benefit from patient advice, and funding agencies are beginning to require it. But what is the best way to collect patient opinions?

Gathering the opinions of thousands of people quickly and affordably has been more of a dream than a reality. Some say it still is. I beg to differ. Indeed, because of the rapid integration of technology and social media into the daily lives of people at all socioeconomic levels and ages, there are now free, fast, and focused ways to gather relevant opinions from various groups of people.

In the past decade, Internet-based interest groups and social media sites have connected people around the world, while technological advances continue to make it easier to meet and share. Online collaboration tools have made special interest groups stronger, more vocal, and very accessible.

Advertisers, pollsters, politicians, businesses, and even individuals began exploiting the trend to tap the public in a new and wide-ranging way. Dubbed *crowdsourcing*, it is basically getting large numbers of members of the public, or segments of the public, to provide you with what you need (opinions, funds, volunteers, etc) via the Internet.

## Testing the tool

Given its potential as a tool for patient engagement, it was important to try crowdsourcing. In the spring of 2012, the Canadian Primary Health Care Research and Innovation Network partnered with Patients Canada (formerly the Patients' Association of Canada) to host a 5-week pilot test in which consumers of primary health care services would engage in the network's priority setting and strategic planning. The goal was to assess the feasibility of crowdsourcing as a means of getting patient input by having consumers answer and generate questions, as well as to debate about issues the network might include in planning.

After a brief search of crowdsourcing tools and a review of cost-free or low-cost platforms, the team chose a platform that offered a free version with basic features, with the option to upgrade seamlessly to the full suite of services at a low cost. A moderator was also appointed to handle the process.

A small number of Patients Canada members (about 100) were informed about the initiative through the group's e-newsletter. After 4 weeks, 5 people agreed to participate. The Canadian Primary Health Care Research and Innovation Network coordinator posed 2 to 3 questions a week, including the following: How can researchers do a better job of involving patients in the design and ongoing implementation of research studies? What should be the top 3 priorities in primary health care research in Canada? How can researchers do a better job of sharing study results with participants? Most of the participants responded to questions regularly. When questions were shared using the platform's notification system, a slightly better response rate was noted. The question that asked for input on the top 3 priorities for primary health care research in Canada had the best response rate.

All told, the pilot test did not work well. The response rate was lower than expected, none of the participants posed questions, and only the platform manager and Patients Canada representatives commented on the responses of others. However, it was not a failure. We learned that despite our flaws in the process—too narrow a pool of possible participants, too short a time frame—crowdsourcing technology holds great potential as a means of gathering patient and consumer input.

## Factors to consider

By its nature—online technology—there are segments of the population that crowdsourcing cannot reach. But even the very elderly, the homeless, and the isolated might have access through family members or workers who will speak for them. I believe primary care researchers in Canada need to consider not whether this tool can inform how we include patients in our work, but how and at what stage. Here is my advice for going forward:

- Decide at what point you want public input (at the conceptual stage [ie, to ask the public if the research is important to them], at the recruitment stage, or at the dissemination stage, or perhaps when suggestions on policy are required) and then find the platform that will work for you.
- Focus on recruiting thousands of people instead of tens of people. Try to appeal to interest groups and social media sites across Canada that would have an interest in what you are doing. Create accounts on various social media outlets (eg, Facebook, Google+,

Twitter, LinkedIn) where you can announce what you are doing and let people know how to connect to your crowdsourcing platform.

- Aim for longer time frames (eg, months) when possible. People come and go, so give them time to connect and express their opinions.
- Do not use crowdsourcing as a sole source of patient input; use it to complement existing approaches to collecting information and feedback from patients.
- Use multiple-choice questions, whenever possible, instead of open-ended questions.

Patient input is integral to our research; patients are, after all, the reason we do research. Crowdsourcing provides us with a new opportunity to capture a vast number of voices at more stages of our research for better, more effective results.



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