Getting Patient Input About Research Priorities

A PLAIN LANGUAGE SUMMARY OF

"Prioritizing Research Topics: a Comparison of Crowdsourcing and Patient Registry" by Anjali Truitt, Sarah Monsell, Andrew Avins, David Nerenz, Sarah Lawrence, Zoya Bauer, Bryan Comstock, Todd Edwards, Donald Patrick, Jeffrey Jarvik, and Danielle Lavallee. Published in Quality of Life Research, April 5, 2017.

Read the original article abstract online: http://bit.ly/2f5QAV5.

What was this study about?

Research topics are often decided by researchers and doctors with little or no input from patients experiencing the conditions being studied. Yet the patients' voice is necessary to ensure that research on their medical condition reflects their needs, especially if patients have concerns their doctors might not think of or understand to be important. Finding people with a particular medical condition to provide input on research may be difficult. In this study, researchers compared two ways of getting input from people with low back pain about research topics that matter most to them. One way was through a registry of people with low back pain who had volunteered to be in research, and the second way was using a general online forum for people wanting to help with survey research.

What did the study team do?

We sent out a survey to ask people with low back pain what research topics they thought were most important to study. The survey was sent to a registry of patients from two healthcare systems who were at least 65 years old and who had seen their doctor about low back pain.

We also sent the survey to people on an online platform called Amazon Mechanical Turk (MTurk), who had signed up to participate in various marketing and research activities., and who also said they experienced low back pain. The survey in both cases contained a list of possible research topics related to low back pain. We asked them to pick the five topics that they thought were most important to study and to rank them in order of importance. The respondents also had a chance to suggest other research topics that were not on the list.

About 900 people from the registry and about 350 people from the MTurk group completed our survey.

How to Get Patient Input About Research Priorities

What did the researchers find?

We found that the respondents from both groups had similar ideas about the most important research topics to study. They tended to rate diagnosis and treatment issues highest in importance – topics such as understanding the causes of low back pain, diagnostic tests, self-care strategies, and ways to preserve physical health. Respondents from the registry were more interested in diagnosis-related research, while the respondents from the MTurk group were more interested in cost-effective treatments and self-care. The respondents from both groups put less importance to research on prevention issues. When we invited them to provide additional research topics, the respondents from both groups listed several new topics that were not on the original list. These included studying medication side effects and drug interactions and ways to reduce stigma around medication use, the impact of low back pain on other health conditions, and alternative treatments such as yoga, pilates, and chiropractic care.

Notably, because there was an age requirement for the registry but no age requirement for the MTurk group, the respondents in the registry tended to be older and most were retired, whereas the respondents in the MTurk group tended to be younger or middle-aged, and employed. However, the groups were similar in terms of gender, race, and education level.

How can you use this research?

Patient registries and online forums are both good ways to reach out to patients and involve them in research. Each has advantages and disadvantages:

- A patient registry is a good way to reach a well-defined patient population. People who sign up to participate in patient registries may be especially knowledgeable about their condition and interested in research. However, it may take resources and effort to build up a patient registry and keep the participants engaged over time.

- An online forum is a good way to reach a broad group of patients from a variety of backgrounds, if the medical condition being studied is a common one like low back pain. Carrying out a survey in an online forum can be quick and done without much expense. However, for less common medical conditions, it may be difficult to find enough participants through an online forum. Some online forums may limit interaction with participants such that ongoing follow-up is not possible

- Social media networks and groups may offer other ways to connect directly with patients and seek their input.

Things you should know:

Patients have important feedback to give researchers regarding what topics are most important to study. They may have different priorities from doctors, and they may also think of new topics that doctors had not considered. Getting input from patients may take some time and effort, but the results are well worth the investment.