



Better Treatment Decisions From More Accessible Research

August 9, 2011 by [Patrick A. Malone](#)

You have lupus, the chronic inflammatory disease in which the body's immune system attacks its tissues and organs. Sometimes the symptoms resemble the joint stiffness and swelling of arthritis; sometimes they present as skin rashes; sometimes your kidneys malfunction. There are four different kinds of lupus whose treatment might involve a variety of behavioral interventions and so many drug options you need a scorecard to keep track.

Even medical professionals specializing in auto-immune disorders can't keep up with the research and vast body of knowledge required to be expert in such a complicated disease, not to mention scores of other disorders whose treatment is situational and varied.

In these days of government that can seem to do no right, one federal program is planning to improve access to the body of medical research knowledge. Established by Congress via the 2010 Patient Protection and Affordable Care Act, the Patient-Centered Outcomes Research Institute (**PCORI**) is

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tasked with identifying the best available information to help patients and their health-care providers make informed decisions about their care.

PCORI, an independent, nonprofit entity, is all about the science.

As noted by Kaiser Health News in collaboration with Philly.com, "**comparative effectiveness research**" is a relatively new concept in the United States. In fact, the U.S. health system, which largely follows a model that pays doctors and hospitals for any service provided, generally has not embraced comparative effective research."

If PCORI brings a much-needed objective, science-based standard to the health-care landscape, that doesn't mean there aren't challenges to its success. After all, it was created by the political process, and when does that ever yield a purely feel-good result?

KHN/Philly.com enumerates several obstacles for the new agency:

- identifying research priorities for patients based on the study of hundreds of medical conditions and the questions they pose;
- avoiding political criticism from opponents who argue that PCORI will ration care, some even calling it a "death panel";
- maintaining support from medical device makers and drug companies concerned that the institute will be simply a cost-control mechanism; and
- devising strategies for conducting studies to provide meaningful results.

PCORI is reviewing past comparative effectiveness research in the hope of making several grants by the end of this year to identify what it needs to find out from patients. For example, should it use social media to ask people what kind of information they want to have before making decisions?

It also wants to warm up the cold, bureaucratic face public programs often present. "[I]n addition to enhancing the quality of the research," said KHN/Philly.com, "reaching out to patients can help the institute shed concerns about rationing that were raised by opponents in the health care debate."

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To protect its objectivity, PCORI is forbidden to consider the cost of different treatments as part of setting its research agenda or drawing conclusions. That makes medical device manufacturers and drug companies, who always are concerned about discussions of cost, more comfortable.

PCORI leaders are highly and widely respected, which also helps solidify its neutrality and depth. The nonpartisan Government Accountability Office selected most of its board members; directors of the National Institutes of Health and the Agency for Healthcare Research and Quality chose the others. The board chairman is vice chancellor health sciences at UCLA and dean of its medical school.

“The basic mission is to insure that patients are well-informed and can have informed conversations with doctors,” Dr. Harold C. Sox, former editor of the Annals of Internal Medicine told KNH/Philly.com .
“Shared decision-making is not a blue-red issue.”

PCORI wants and needs consumer input throughout its mission. This month, it’s soliciting input from the public about initial topics for pilot projects. To learn more, [link here](#). To stay informed about what PCORI wants to know from consumers, and to contribute to the conversation, [link here](#).

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