

Multiple sclerosis patients see drug value differently than payers and doctors

By [Ed Silverman @Pharmalot](#)

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A patient holds the medications she takes to slow the progression of her multiple sclerosis. *Rogelio V. Solis/AP*

When it comes to medicines, value is often in the eye of the beholder.

A new analysis finds that what multiple sclerosis patients value in their medicines is generally overlooked by payers and doctors. As a result, drug companies subsequently disregard what matters most to patients, according to Real Endpoints, a research firm that conducted the analysis.

Specifically, the firm found that payers and physicians place much more emphasis than patients on the extent to which a medicine affects the progression of multiple sclerosis, prevents relapses, and the severity of any relapses.

By contrast, multiple sclerosis patients expressed greater concern about the risk of developing serious side effects or a rare brain disease known as PML associated with certain drugs. In particular, they were also more concerned with out-of-pocket costs.

The analysis involved reviewing more than 300 medical studies and surveying 30 payers, 30 doctors, and 30 patients. The exercise was funded, by the way, by the Pharmaceutical Research and Manufacturers of America, the industry trade group.

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“The key point is that coverage decisions and physician prescribing do not take into account the most important patient preferences. And drug makers then follow the lead of the payers and physicians in designing their clinical trials. So at the end of the day, their notion of value is much different than what the patient values,” said Roger Longman, who heads the firm.

“Theoretically, we are in a patient-centric world. But drug companies should not merely focus on endpoints or metrics that are FDA-approved or focus on payers and physicians,” he continued. “Given the way the world is moving, where patients are becoming a louder and more powerful voice in prescribing, drug companies need to be testing for those endpoints important to patients.”

This sort of disconnect may help, in part, to explain the widening gulf between patients and the pharmaceutical industry. Over the past few years, Americans have expressed intensifying anger over the cost of medicines, whether these are newly approved treatments or older drugs for which prices were raised to sky-high levels.

But the complicated US drug pricing system does not allow for easy fixes. And unlike some other countries, there is no government entity or mechanism to determine whether a drug is cost effective, although various tools are gradually filling the void. The new analysis, however, suggests that easing patient anger will require paying attention to patient preferences, and cost may be just one factor.

“If you’re assessing the value of a treatment, you do want to know what the patient is thinking,” said Kimberly Westrich, vice president of health services research at the National Pharmaceutical Council, an industry-backed group that studies value and access issues.

“Unfortunately, you can’t capture this information in a traditional competitive effectiveness analysis. But if the pharmaceutical industry knows there’s an appetite for this kind of information, which can be shared with payers and treatment guidelines developers, they may choose to start building these points into their trials so there is available data.”

It is true, however, that competitive effective analyses are evolving. The Institute for Clinical Effectiveness and Review, which regularly evaluates drugs in different therapeutic classes, as well as the American Society of Clinical Oncology and the National Comprehensive Cancer Network, are looking to incorporate issues that matter to patients.

The National Multiple Sclerosis Society told us that a recent survey conducted with ICER found that 90 percent of people with MS reported that the ability to continue working, or resume normal activities, was an important or very important factor in deciding which drug was right for them.

“While not familiar with this particular study, we do believe that the patient perspective and voice should be fully integrated into decisions about treatment options including in formulary design and value assessments,” said Bari Talente, executive vice president of advocacy at the National Multiple Sclerosis Society.

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