

# PERSPECTIVE

## Patient Assistance Programs: Information Is Not Our Enemy

The authors respond to criticisms of their research on how well PAPs assist with the purchase of vital medicines.

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KEN JOHNSON OF Pharmaceutical Research and Manufacturers of America (PhRMA) and Myrl Weinberg of the National Health Council take issue with findings from our survey of drug company-sponsored patient assistance programs (PAPs).<sup>1</sup> Our disagreement is partly the result of a healthy debate on how best to structure our health care system. More problematic are the commentaries' mischaracterizations about our study's intent and findings. This distracts from the goal of helping patients who need help the most.

### Where We Disagree

**■ Process versus outcome.** We surveyed drug company-sponsored PAPs to better understand the application process and the comprehensiveness of coverage. In our paper, we raise a concern that the process of applying for assistance may be burdensome. Despite the "user-friendliness" of the Partnership for Prescription Assistance (PPA) Web site, many patients with chronic diseases must fill out multiple complex applications, as most programs cover only one or two medications. Our results are consistent with the observations of others.<sup>2</sup> We were unable to determine how many patients have been helped by drug company-sponsored PAPs, because the vast majority of companies refused to tell us. Further, the implications of PAPs for public-sector health spending are unclear. Johnson interprets our findings and the legitimate questions we raise

as "a disservice to untold millions of financially struggling Americans who could benefit" from PAPs. If the outcome that we all seek is to maximize access to essential medications, then optimizing the process by which they do so will help these "untold" millions; failing to do so is the real disservice.

**■ Information is not regulation.** Johnson repeatedly misrepresents us as advocates of increased regulation of PAPs by "mandatory review and data collection for these programs through a government-run edict." This is a clear distortion. We support collecting more information about drug company-sponsored PAPs to better understand the benefits they offer. Although existing federal law could be used to compel drug companies to report how many patients they have directly helped, we caution that "forcing the release of this information may unnecessarily antagonize corporations that legitimately seek to help patients with inadequate coverage." This information should be of interest to patients, providers, payers (including insurance companies), and the drug companies themselves in achieving the goal of improved medication access.

**■ Standards of evidence.** Johnson claims that our analysis is "based on anecdotal observations." We offer no anecdote in our paper—we objectively present data and fully describe how they were collected. In contrast, Johnson begins by telling the story of one patient, Shirley Sobolewski. He continues by offering statistics from a non-publicly accessible, non-

peer-reviewed survey. Johnson may be well served to look up the definition of "anecdote."

**Misplaced or misquoted?** Johnson states that "in these authors' view, patients' confidence [in drug company-sponsored PAPs] is 'potentially misplaced.'" This is a blatant misquotation. We say nothing about patients' confidence being misplaced. Rather, we contend that "the public's reliance on [drug company-sponsored PAPs] and the resources devoted to them, albeit from private industry, are potentially misplaced" if few patients are able to navigate their application processes. Conversely, we suggest that if many successfully use PAPs, then the adequacy of public prescription coverage should be reevaluated. We simply call for more information to better understand the process of use and the extent to which these programs serve as a safety net.

**The real "real world."** Weinberg believes that our analysis "ignores the real-world implications of its own conclusions" and that a more practical solution is to "tackle fundamental problems facing an overburdened health care system." Although universal health care may be our ultimate goal, to assert that we should only spend our time envisioning a perfect health system ignores the reality that in the interim, the current fragmented one must continue to function. In the real world, publicly funded safety-net clinics, patients, and providers spend time, effort, and money accessing PAPs. Determining whether these limited resources are being used effectively is certainly in the public interest. In the absence of fundamental reform, does Weinberg propose that we stop seeking incremental solutions, such as the Children's Health Insurance Program (CHIP), to help vulnerable patients?

**Information is not our enemy.** Weinberg states that the information we call for "would come at a cost, and part of the cost would be a major reduction in access to prescription drugs for those who need them the most." This is conjecture. The data we see as being important need not be onerous or costly to collect and need not undermine the mission of broader health reform. As Weinberg herself acknowledges, we recommend that the choice

of information-gathering methods must avoid unnecessarily punitive action against companies that seek to do good and further marginalization of those patients who are most in need. Learning more about drug company-sponsored PAPs may help more patients obtain the drugs they need. These data will also help us understand how patients navigate our complex health care system; this will be useful for structuring the broader health reform for which Weinberg calls.

### The Bottom Line

Access to essential medications is a major issue in the United States. Based on our survey, we conclude that drug company-sponsored PAPs "collectively cover the most widely prescribed brand-name medications in the United States" and that they "help some patients obtain important medications." This notwithstanding, the number of patients helped by drug company-sponsored PAPs, their ability to navigate these and other drug benefit programs, and the equitability of relief could be improved with more information that is collected in an efficient, nonpunitive, and thoughtful manner. We agree that more comprehensive coverage is the ultimate goal and would obviate the need for drug company-sponsored PAPs. In the meantime, all parties gain from a better understanding of how these programs work, especially as we invest public funds to help patients use them.

### NOTES

1. K. Johnson, "Voluntary Patient Assistance Programs: Additional Federal Oversight Unwarranted," *Health Affairs* 28, no. 3 (2009): 835–838; and M. Weinberg, "Reforming Patient Assistance Programs: Perfect World Meets Real World," *Health Affairs* 28, no. 3 (2009): 839–842.
2. D. Chauncey et al., "Medication Access through Patient Assistance Programs," *American Journal of Health-System Pharmacy* 63, no. 13 (2006): 1254–1259; and M. Sarrafizadeh et al., "Pharmacist-Facilitated Enrollment in Medication Assistance Programs in a Private Ambulatory Care Clinic," *American Journal of Health-System Pharmacy* 61, no. 17 (2004): 1816–1820.