

“The Pink Sheet” DAILY

OCTOBER 10, 2013

CMS Needs Payment Reform Ideas For Rare Diseases From Private Sector – Former Official

Speaking to a DIA/NORD conference, former Center for Medicare and Medicaid Innovation official William Shrank agreed that the agency’s current experiments in payment reform are not designed to accommodate rare disease patients.

The biopharmaceutical industry and patient advocacy groups should develop ideas for tailoring federal government payment reforms to rare disease patients and present them to CMS, suggested William Shrank, former director of rapid-cycle evaluation at the agency’s Center for Medicare and Medicaid Innovation.

Speaking to the DIA/NORD conference on rare disease and orphan products Oct. 9, Shrank agreed that current experiments in government reimbursement reform are not designed specifically to accommodate the needs of rare disease patients. He also acknowledged the need for casting a wide net, both in the U.S. and abroad, for ideas that would promote improving the quality of care while lowering costs in that space.

However, “if we wait for CMS to perform that analysis we may age into different kinds of care ourselves,” he observed. “I would think you’re in a unique spot to conduct some of those systematic reviews and produce them. And the more evidence that comes out of the private sector that says, ‘We can do this better. We can actually deliver higher quality, lower cost care. Here’s some evidence, not from the U.S. but from elsewhere,’ that’s what CMS needs.”

“So I would encourage you to do it on your own, publish it and bring it to CMS,” he concluded.

While at CMS, Shrank led evaluation of all payment and health-system reform programs funded by the innovation center. The center was established by the Affordable Care Act to foster the development of reforms

(“New Drug Payment/Delivery Models Sought For CMS Innovation Grants” — “The Pink Sheet” DAILY, May 15, 2013).

Shrank now serves as part-time faculty in the division of pharmacoepidemiology and pharmacoconomics at Brigham and Women’s Hospital and is principal investigator of the CVS Caremark Harvard

Partnership for improving medication adherence and the Pharmacy Care Research Institute, also funded by CVS Caremark (*“CVS Caremark Part D Plans Collaborating With Medicare ACOs On Drug Adherence” — “The Pink Sheet” DAILY, Jun. 27, 2013.*

His suggestion to the conference responded to comments from audience members that current CMS experiments in payment reform, such as accountable care organizations, focus mainly on the broader primary care population and may disadvantage rare disease patients.

While maintaining that the general concept behind ACOs should work for rare disease patients, Shrank recognized the concern that the model might produce disincentives to seeking the highest quality care for rare disorders.

“It’s not in an ACO’s best interest to limit access to the best providers for people who really need it,” he maintained. “When you look at the Pioneer ACOs, the big ACOS that are willing to take risks, all of them ... I’d venture to guess, have some sort of specialized effort around a large proportion of these kinds of complex, chronic and even relatively rare conditions.”

“If you have a person [managed by an ACO] with a rare disorder, and they’re racking up charges left and right ... those providers are going to get really nervous really fast, because they don’t know the disease, they don’t know how to treat it, they just know it’s getting expensive.”

– BioMarin’s Suter.

Under the Pioneer ACO program, funded by the CMS innovation center, participating groups of coordinated health care providers can earn a share of the savings they generate by providing less costly care, as long as they meet certain quality benchmarks. They are also at financial risk if they can't beat the efficiency thresholds. Twenty-three health care systems are participating, including Montefiore Medical Center in New York and Partners Healthcare in Boston.

"But I hear your concern here," Shrank continued, that the best care for rare disease is likely to be more expensive. "And we don't want to lose the value we're getting" through organizations specializing in rare disease "because they're actually helping people."

Rare Disease Payment Bundles

He suggested that one remedy might be found in bundling health care payments based on a rare condition, such as cystic fibrosis. "If there was a cystic fibrosis bundle, it would be those specialists, the best experts in the world that would be sitting around the table to say, 'How do we build it?'" and "I think that would be really reassuring," he pointed out. However, "if or when that happens, I can't speak to."

One audience member raising questions about CMS' payment experiments was BioMarin Pharmaceutical Inc.'s Ruth Suter, senior director of market access and patient

services at the company. BioMarin markets ultra orphan drugs that treat a group of inherited metabolic disorders known collectively as mucopolysaccharidosis (*"BioMarin Preps For Vimizim Launch, Its Largest Yet"* — *"The Pink Sheet"* DAILY, Sep. 17, 2013).

Suter acknowledged that ACOs are not intended to allow cost considerations to outweigh appropriate care for rare diseases. But she pointed out that health care providers operating in the organization who are unfamiliar with the condition may lean that way.

"We've seen that dynamic happen pretty frequently," she said. "If you have a person [managed by the ACO] with a rare disorder, and they're racking up charges left and right ... those providers are going to get really nervous really fast, because they don't know the disease, they don't know how to treat it, they just know it's getting expensive."

If "you take that back and appeal it to the ACO, the ACO is going to respond exactly the way you did, but in the meantime, it takes a pretty savvy consumer to be able to navigate that particular process," Suter said. "And since we haven't seen any regulations ... around that, we just like to use it as a practical example of some things we'll have to work through with [payment reforms established under] the ACA."

By Cathy Kelly