Participatory Medicine is a movement in which networked patients shift from being mere passengers to responsible drivers of their health, and in which providers encourage and value them as full partners. 1

The elections are over, and now the work begins.

In September, the Institute of Medicine’s Best Care at Lower Cost1 cited $750 billion of unnecessary spending in US health care. The authors laid out a wide range of actions to create a “continuously learning healthcare system” to foster the improvements that will get us to the new world where care works better. Ironically, and tellingly, with billions to be saved, the question people ask is whether we can afford to do it.

This is an expression of powerlessness.

In the e-patient movement, we know that an empowered person assesses their options and acts; a disempowered person shrugs, hopelessly, and says, “What am I gonna do? I don’t have any options!” And yes, people in the business can be disempowered, too.

That’s a Lot of Money

It is hard to imagine how much money must be cut—how much revenue will stop flowing into one pocket or another. Being a businessman, I sized it up this way: Imagine if all these companies went out of business:

<table>
<thead>
<tr>
<th>Company</th>
<th>Revenue</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intel</td>
<td>$54 B</td>
</tr>
<tr>
<td>Microsoft</td>
<td>70 B</td>
</tr>
<tr>
<td>Apple</td>
<td>100 B</td>
</tr>
<tr>
<td>Ford</td>
<td>136 B</td>
</tr>
<tr>
<td>Chrysler</td>
<td>55 B</td>
</tr>
<tr>
<td>GM</td>
<td>150 B</td>
</tr>
<tr>
<td>Dell</td>
<td>63 B</td>
</tr>
<tr>
<td>IBM</td>
<td>107 B</td>
</tr>
<tr>
<td>Total</td>
<td>$735 B</td>
</tr>
</tbody>
</table>

It’s not just the revenue itself and the thousands of jobs that will be affected from clerical to C suite; when that much revenue disappears, the impact is seismic. The fights have already begun: Providers resist shrinking reimbursement by balance-billing patients, to which insurers sometimes respond by telling patients not to pay.

We must improve, we must cut—but the best must be preserved. And that begs the question: Who says what’s best?

Some say patients. Others say that’s crazy.

“Patients are Lousy Consumers”

At TEDMED 2012, a speaker from a commercial lab service said patients make lousy consumers. I thought, “Really?! Really?!” I thought of last fall. With $10,000 deductible health insurance, I shop carefully, and I’ve learned it’s really hard to research my options. A CT last fall cost me $1,736; this spring, after arduous research, my next one cost $260.

In the process, I shopped for some blood tests, and the insulting speaker’s lab company said they couldn’t tell me what it would cost me through my insurance.

Makes it hard to be a good consumer, right? And this isn’t just a patient rights issue; if nobody knows the prices, it’s hard to optimize spending.

And here’s the twist: I called my insurance company, and they couldn’t tell me either.

The reason, it seems, is that my New Hampshire Health Plan (for high-risk patients like me) is only a customer service firm, with no access to costs and pricing; a TPA (Third Party Administrator) has the business relationship with providers. They negotiate prices, and I’m not allowed to talk to them.

Suddenly, I understood what Uwe Reinhardt meant when he described health care pricing as “chaos behind a veil of secrecy.”

As we start to shrink spending, we need to know where the waste is, and I say that process doesn’t begin until the prices are visible.

I Said “Visible,” not Transparent

“Transparent” is abstract. When a restaurant’s martini menu lacks prices, I don’t ask for transparency—I ask, “What does this cost?” What we need in health care is both quality data and visible pricing. Without that, we have no idea which providers do a great job for less and should benefit from the change.

Skin in the Game—My Own, This Time

To say patients have no skin in the game is ironic and insensitive. About 75,000 deaths would be prevented if every state were as good as the best. 1 That’s skin in the game, health leaders: funerals that the best providers prevent. Fix that. The best of you should be preserved and publicized to consumers.

Last January my skin got in the game literally and figuratively: I was diagnosed with a basal cell carcinoma and faced thousands in costs. This time I refused to be a victim of my bills—disempowered—so I took to the blogs and published an RFP (Request For Proposals). I said that I...
wanted to know what my costs would be but that I wouldn’t choose the low-price bidder; I just wanted to know what my options were. And, I said, “If you don’t know what your costs are, you’re part of the problem.”

I got no responses. (What hospital has an RFP response team?)

So, empowered and proactive, I called around and got drastic variation in answers. So time after time, I asked, “Is that all?” “What else will show up on my bill?” “What else?” It took months to get responses. After three months of investigation, instead of paying $5,000 to $7,000, I opted for a less sophisticated procedure with more of a scar and a higher risk of recurrence and paid $696. (The surgeon gladly gave me the literature citation when I asked.)

Note: None of the hospitals offered me that option, even when I asked. I got it from other dermatologists, commenting on my blog.

**Nothing is a More Personal Choice than My Health Priorities**

In no way would I recommend that someone else choose what I chose. I have my priorities, which surely don’t match another’s. All I want is for people to have choices, with reliable information on quality and costs. As a free enterprise guy, I believe that those conditions will ultimately lead to efficiency and rewards for the most skilled.

That’s important because I want every one of my providers to do well during the change. They’re capable, and they’re patient centered. And I believe that compared to our norm, they provide better care, at lower cost. I want them rewarded.

**References**

2. Source: the companies’ Wikipedia pages (accessed October 20, 2012)
3. http://content.healthaffairs.org/content/25/1/57.abstract