

# A Populist's Wish List for Patient Empowerment

written by Theresa Hush | December 7, 2016



Health care turmoil of the last 10 years was wild enough, but the ride ahead promises to be even wilder.

News and social media are swirling with proposals to “reset” health care. Among the dizzying array of possible scenarios, one idea is gaining traction: patient “empowerment.” It will, without doubt, be a prominent call-to-arms in the months ahead.

But, what exactly is patient empowerment? The newly branded concepts presented in health care proposals are murky and incorporate everything from patient responsibility for lifestyle changes and following treatment plans (patient “compliance”) to greater financial responsibility for health care (shared premiums).

Patient empowerment can hide a lot of sins, like simple [cost-shifting to patients](#) and away from employers, insurers and providers. Unless sharing of financial responsibility is backed by more efficiency and effectiveness in the health care, however, the resulting system will not be sustainable. It’s worth examining how a real empowerment of patients can be a positive force for both better health and cost control.

## Patient Premium Sharing and Vouchers Are Not Real Empowerment

There's nothing new about shifting more financial responsibility onto patients. After all, that's how copays and deductibles came into being. It's appropriate for patients to share some proportion of expenses of the health care they receive, although some would disagree with this on the grounds of either social or tax policy.

But a wholesale restructuring of benefit programs into "vouchers" for purchasing health care is merely a bandage for reform. Vouchers shift the problem of excessive costs to consumers who are currently at a huge disadvantage:

Health care consumers don't understand what they are buying, nor can they judge the effectiveness or alternatives of proposed treatments;

They don't know the cost of what they are purchasing - not only because the "prices" they see aren't real and are communicated after-the-fact, but also because prices are too complex and levied by too many different parts of the health care system;

They can't compare costs or treatments among alternative providers of care, because they have no comparative data to accurately identify alternative treatments or even providers. There is no central data bank on providers.

## Value Is Unknown in Health Care Purchasing Decisions

Shopping for health care isn't like shopping for intuitive, tangible products. Patients are told what they should "buy," but have no deep understanding of what went into those physician decisions. Information about how a certain treatment will benefit their unique makeup in measurable ways is often unknown. Will they extend their lives by a few weeks or years, or improve their functionality for one year or ten?

Even many basic lifestyle choices are not clearly linked to value of a particular treatment. Take a look at recent headlines. Many cancers resist cure, and many treatments cause secondary cancer. [Cholesterol](#) is no longer the sole villain it was presumed to be in cardiac care, and in many cases is flat-out invalid. Pushing hemoglobin A1C to very low levels, as once recommended, is now known to be harmful.

Too much is still unknown about health care outcomes and how to achieve them. The "optimal" treatment may be calculated from imperfect clinical trials or surgical experience (also trials of a sort), yet the effect on an individual patient is usually not known. Why? Because outcomes are not always linear, and treatment modalities often emerge from imperfect research or are based on an "average" patient.

The level of treatment benefit is rarely discussed between physicians and patients. Physicians

are programmed to make decisions and, with the best intentions, steer patients to treatments based on likelihood of success. This is well and good, but the individual patient—whose genetic and environmental mix may be very different from average and is almost always unknown—may have unpredictable outcomes.

Nor are costs typically discussed. Patients often receive one recommendation or, at best, the “Do This” or “Do Nothing” options. Alternatives may or may not be part of the conversation; even if some costs are presented, information is limited to the presenting physician’s fees and does not include all of the associated facility, laboratory, pathology and other expenses. Not to mention, failing to go forward with a physician’s recommended treatment will reflect negatively on the patient.

### Cost and Pricing Are a Complete Mystery to Health Care Consumers

In addition to understanding value, consumers can’t possibly understand the complex financial “pricing” that goes with health care. As most insiders know, there really isn’t a set price—most health care fees are negotiated, except when it comes to the patient portion. That’s why a fee that is billed has a different “approved” amount, or why an unapproved amount may be written off by the provider

Let’s be honest. Most consumers can’t understand their [Explanations of Benefits](#) that come after a claim is submitted, nor do they understand why bills come from so many places or providers. They don’t understand a facility bill, especially if it includes doctors, versus a physician’s bill. That’s because the whole billing and claims payment process is overly complicated for the actual care delivered.

Consumers may understand that if they go to the doctor, they must pay a \$30 or more copayment, but they don’t know how much, or how little, that amount is relative to the total bill—or, how the total fee compares to other physicians.

### Finding and Comparing Providers is Impossible

Consumers cannot easily compare providers. This is a huge understatement. At best, they may surf a “provider network” list for possible options. What information do they get? Just the name, gender, place of degree and, possibly, training, language spoken and specialty or areas of interest. Maybe they get a picture. This is the equivalent of choosing a house with just a street address, number of rooms, square footage and a thumbnail image—not even an asking price.

Few consumers know how to compare the credentials or the approach of one physician versus another. They don’t have any data to compare costs. And, since the quality ratings (if there are any, which is rare) differ from insurance company to insurance company, anything they find on

quality could be conflicting or confusing.

Most importantly, without meeting in person, consumers can't possibly know how a particular physician is going to work with them. The physician may or may not be willing to have a good conversation about their wishes, or may simply direct them to treatment. But, trusting, communicative relationships are the foundation of quality health care.

## What Consumers Need for Intelligent and Cost-Conscious Health Decisions

Knowledge of real facts about personal health care status and treatment options. It's time for consumers to be connected to research results—with metrics that point to the universality or validity of those results as they relate to individual situations. It is a basic right to be an [active participant in health care decisions](#) instead of a passive part of the process. Consumers need to know when the facts about diagnoses and possible treatments are fuzzy. They also need to know the possible risks and benefits of any interventions.

Comparative provider information on cost and outcomes. No “grading” system will be foolproof, but there must be an objective starting point for consumers to select providers. For consumers to make intelligent choices about health care purchases, they must have access to reliable information about provider service, quality and outcomes associated with their patients. This translates into more, not less, emphasis on validating data for outcomes—and requires more provider and patient feedback about results. Data is imperfect and must be supplemented with qualitative and patient-reported outcomes. The data should be universally applied, not payer-by-payer, to be relevant to consumers. Finally, consumers should be able to have easy, universal access to these results.

Clean, unfiltered access to personal health care records. The debate on [who owns patient data](#) should always be answered in favor of the patient. If consumers are to be responsible, they should not have to ask for their data, nor argue to get it after review by a physician. To physicians who believe it's unfair to worry patients with test results that are not filtered or explained, I can only say: ask your patients what they want, because you may be surprised. In today's online world, consumers are used to researching and interpreting the data. They want to hold the cards.

Ability to send personal health care records to another party. In another take on the ownership of patient data, most consumers want to be able to direct their records, without undue hassle, to other providers. For that matter, they may also be likely, in the future, to want to direct their data to third party entities for analysis, insight, consultation or personal assistance. This positive step in taking responsibility gets to the essence of patient “empowerment”: a pro-active role in personal health care.

Complete transparency of fees and what consumers must pay up-front. The mystery of fees must disappear to end consumer (and provider) confusion and frustration. Of course,

this is easier said than done, and it may take many iterations to get it right. But patients need to understand the full cost of every intervention and extended treatment plan, and understand what will be and will not be covered by their carrier. The fine print on provider assistants, facility fees and physician fees, and miscellaneous charges all need to be revealed so consumers can make intelligent purchasing decisions and arrangements. Real cost information. Price is one thing, and [cost is another](#). The cost of getting services from one provider, or in one location, compared to another, vary considerably, and consumers have a right to understand their real choices. This includes information on cost before they select their coverage options. Are they being steered to providers in networks solely on the basis of cost? How do insurance plan networks compare on both quality and cost metrics? While everyone agrees that no risk adjustment scheme is perfect, it should be mandatory for comparisons to include risk-adjusted quality and cost figures so that tertiary or complex specialty providers are not unfairly presented.

Participation in trials and research. Methods of selecting patients for research are still primitive and pre-Internet. In addition, given that [clinical trials](#) raise many issues regarding limited populations and exclusions, we should seek to develop a more populist version of research. Why shouldn't every patient have an option to include personal data in a research design? If they had the freedom to send their data for external analysis and research, might this be a way to achieve much greater capacity for evaluating the prevalence and contributory factors to health and disease, along with the effectiveness of interventions?

Equivalent, comparable information on health plan coverage, provider options and guarantees on selections. Access to health care begins with the selection of insurance or health plan coverage. The insurer's quality and commitment is an important determinant of the product received by the consumer. But one of the biggest unknowns for consumers is the inclusion of the physician and hospital network associated with a health or benefit plan and what this means for continuation of care. Consumers should have an easy, accessible way to compare networks, and the providers associated with the networks, as well as the plan benefits. Further, consumers should not get a "bait and switch" on health plan choice—once they select a plan based on the participating providers (which may well be their own), the continued eligibility of that provider for the enrolled patient should be guaranteed during the enrollment year.

It's a long Wish List for consumers. We in health care have a long list about what patients should do, but many of those wishes are really about what makes it easier for us. If we are going to empower patients, it is incumbent on us to make it easier for them.

*Founded as ICLOPS in 2002, Roji Health Intelligence guides health care systems, providers and patients on the path to better health through [Solutions](#) that help providers improve their value and succeed in Risk. Roji Health Intelligence is a CMS Qualified Clinical Data Registry.*

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