The United States spends nearly $2.7 trillion on health care annually, and its major public health insurance programs, Medicare and Medicaid, represent about 20 percent of the federal budget. The amount of money is not necessarily a problem, but there are reasons to believe that this money is not spent wisely. International comparisons suggest that the U.S. does not get a good return on its health care spending. If we focus only on measures of health that can be influenced by health care, like mortality that medical attention may have prevented, the U.S. does far worse than countries that spend less on health [1-3]. Domestically, analysis from the Dartmouth Atlas Project also raises questions about the effectiveness of our health care spending [4]. There are enormous geographic variations in spending that do not correlate with the needs of patients in those areas or with outcomes. Although many expensive medical technologies represent good “value for money” [5], others, it seems, do not.

Beyond efforts to calculate the return on investment associated with particular technologies is the question of how to set priorities. Even if we limit spending to interventions for which there is a strong evidence base, this does not address the question of whether we are directing our resources toward diseases, conditions, or determinants of health where they would have the greatest effect. In terms of research, many studies claim that the NIH may not target diseases and conditions that represent the greatest burden to society, whether burden is measured in terms of mortality, disability-adjusted life-years, or cost [6]. One study found that some cancers, like breast and prostate cancer, receive a share of research funding that exceeds the burden they impose on society, while other forms of cancer, like bladder cancer, receive a far lower share of funding in relation to their societal burden [7].

The mismatch articulated by the study above between where spending goes and where it is most needed is not limited to research. Many argue that our health care delivery and finance systems place too much emphasis on specialty care and not enough on primary care. Advocates who argue for increased spending on prevention often point out that “only” 5 percent of the money spent on health care is devoted to population-wide approaches to health improvement [8]. The U.S. health care system provides far greater financial rewards for treating illness than it does for keeping people healthy. The makeup of the health care workforce and the methods we use to pay physicians reflect these priorities. In every other developed nation, about half of all physicians work in primary care; in the U.S. only one-third do [9]. The lack in primary care workforce is perpetuated by reimbursement policies that reward
specialty care services at a higher rate than primary care, discouraging medical students from pursuing primary care as a career [10].

Why is there such an apparent mismatch between what our spending priorities ought to be and the actual allocation of funds? Differences in wealth, which often translate into greater political power, offer a partial explanation. Some public health advocates expressed with alarm [11] the fear that the *Citizens United* decision, in which the Supreme Court ruled that the government cannot limit corporate independent expenditures for advocacy advertising during election campaigns [11], could doom public health policies that conflict with corporate interests. Consistent with this view, one study found that disease groups with sufficient resources to lobby Congress are able to affect NIH funding priorities by influencing congressional earmarks [12].

There are times when groups without a great financial advantage organize effectively and increase the treatment available for a particular condition or set of patients. HIV/AIDS activists forced the FDA to adopt major changes in the drug approval process. Breast cancer advocates changed the research priorities of the federal government and forced the health care system to change the way it treated patients with this disease [13, 14].

But the patient-activism model is limited because not all patients are equally likely to participate in the health policy process [14]. Furthermore, the success of patient groups that do participate in the process may have little to do with the merits of their demands or efforts of their members. The personal experiences of celebrities or policy makers may lead them to champion the cause of certain patient groups and increase the probability of success [15]. When a member of Congress has a personal experience with a disease or set of diseases, he or she is more likely to support spending on these conditions.

The degree to which patients suffering from the disease are viewed as “deserving” can also influence public support and spending patterns. Support for patients living with HIV/AIDS, a disease that was originally associated exclusively with gay men, increased significantly thanks to media coverage of Ryan White, a teenager who contracted HIV after receiving infected blood to treat his hemophilia in the mid-1980s. The perception of deservingness, reasonable or not, is a powerful force in the political process and shapes who gets what from government.

How should we set priorities for health care spending? More than a decade ago, Daniel Callahan reviewed competing ethical principles, as well as efforts by health policy researchers to create formulas that could be used to set priorities for health care spending [16]. He found objections to all of the above. Measures of burden that emphasize mortality may lead us to invest too little in chronic diseases that reduce the quality of our lives but not always their length. Measures of burden that emphasize health expenditure may lead us to ignore diseases that lead to rapid death and, as a result, cost very little. Instead, he advocated using “the political method of setting priorities.” He argued that, “it is familiar, messy, and yet comparatively
Callahan’s claim that no formulas or broad principles can substitute for a political process when determining priorities in health care is compelling. The question is whether it is possible to construct a political process that is less likely to be unfairly dominated by those with greater wealth, those who happen to share a disease with someone in a position of power, or those who are simply considered more attractive than other sick people. Is it possible to create a process that is fair? Given the history of health policy in the U.S., this is no easy task.

Advocates of deliberative democracy hope to create forums in which participants make decisions on the basis of reasons “that can be accepted by those who are bound by it” [17]. These advocates reason that when more people are involved in the decision making process there is a greater chance that those affected by a decision have an opportunity to influence it [18]. Creating a more participatory, more deliberative process is challenging, but not impossible. Identifying strategies for creating a deliberative process is important because our best hope to improve the allocation of health care resources is to improve the political system that shapes these decisions.

Several federal agencies, including the Agency for Healthcare Quality and Research, the Institute of Medicine, and the U.S. Food and Drug Administration are exploring more deliberative processes for shaping health policy decisions. None of these agencies, nor the academic researchers who focus on deliberative democracy, have identified an ideal process. There are, however, questions that all efforts at deliberation must address to be successful. Who are the relevant stakeholders? How representative are participants in the deliberative process? What decision rules will govern the deliberative process? Will the deliberation be moderated by a “neutral” party? Who will be responsible for vetting the background material that the group will use in their deliberations? Will the process be a one-time interaction or will participants have a chance to meet with each other over a period of time?

One-time interactions in the form of polling a representative sample of the public may be valuable, but these efforts cannot substitute for regular meetings among stakeholders. Doing this, however, requires a substantial commitment of time and other resources and may exclude some people from the process. How to balance the desire for inclusivity with the value of frequent meetings can have a profound effect on the outcome of the deliberation—but it is a question without an obvious answer. The answers to all of the questions listed above can shape outcome of these deliberations and their perceived legitimacy. Calls for deliberation are ubiquitous, but unless we work to reach consensus on what constitutes a fair process, efforts to use a deliberative process will be met with disappointment [17].
References


Michael K. Gusmano, PhD, is an associate professor of health policy and management at New York Medical College in Valhalla and a research scholar at The Hastings Center. Dr. Gusmano’s research interests include the politics of health care reform, comparative health systems, aging, health and health care inequalities, and normative theories of policy analysis. His most recent book, Health Care in World Cities (Johns Hopkins University Press, 2010), documents the implications of national and local health care policies for access to care in New York, London, and Paris.

**Related in VM**

Priority Setting in Biomedical Research, April 2009

Research Funding Favors Allopathic Medications, March 2008

---

The viewpoints expressed on this site are those of the authors and do not necessarily reflect the views and policies of the AMA.

Copyright 2012 American Medical Association. All rights reserved.