I argue that an ethical vision resting on explicitly articulated values and norms is critical to ensuring comprehensive health reform. Reform requires a consensus on the public good transcending self-interest and narrow agendas and underpinning collective action for universal coverage.

In what I call shared health governance, individuals, providers, and institutions all have essential roles in achieving health goals and work together to create a positive environment for health.

This ethical paradigm provides (1) reasoned consensus through a joint scientific and deliberative approach to judge the value of a health care intervention; (2) a method for achieving consensus that differs from aggregate tools such as a strict majority vote; (3) combined technical and ethical rationality for collective choice; (4) a joint clinical and economic approach combining efficiency with equity, but with economic solutions following and complementing clinical progress; and (5) protection for disabled individuals from discrimination. (Am J Public Health. 2008;98: 1756–1763. doi:10.2105/AJPH.2007.121350)

IN THIS ARTICLE, I OFFER AN alternative approach to health system reform in the United States, which I call shared health governance, that is part of an alternative theory of health ethics. The basic ethical commitment to “human flourishing” underlies society’s obligation to maintain and improve health, under this paradigm. Public policy should focus on individuals’ ability to function. Health policy should support individuals’ health capabilities by enabling them to meet their health needs and by fostering what I call health agency (i.e., people’s ability to make health decisions and pursue health goals).

This ethic encompasses several key principles for health policy and reform. First, it assigns special moral importance to what I call health capability, a person’s ability to be healthy. This contrasts with the view that health care is special because of its impact on equality of opportunity and the utilitarian view that health care is important for maximizing social welfare. Equality of opportunity, for example, results from “[a] time or condition [favorable] for a particular action or aim,” as when individuals have equal access to employment opportunities, and utility connotes desire or pleasure.

Second, this paradigm argues for valuing “central health capabilities” above those that are secondary. Agreement on such core health capabilities can provide guidance in prioritizing health care goods and services. This approach can help determine whether a particular medical intervention or technology merits societal resources.

Third, this paradigm proposes a joint scientific and deliberative approach to evaluating public health and health care interventions. It combines the evidence base of medicine and public health, expert opinions from health professionals, and input...
from individuals. Individuals, as change agents for their own behavior and for public policy at large, must be able to participate in deliberations and decision making and must be informed of the risks, benefits, and costs of various health policy, prevention, and treatment options.

This view contrasts with paradigms in which health care decisions are made by consumers, physicians or public health experts, or third parties such as insurers alone, as well as with paradigms in which such decisions are made via strict algorithms, cost–benefit calculations, or shared decision making within an informed consent model. In shared health governance, individuals, providers, and institutions work together to empower individuals and create a positive environment for all to be healthy.

This approach also differs from efforts to develop a decision-making process designed “to set fair limits on health care.” It calls for consensus on substantive principles and procedures of distribution and offers a method for achieving such consensus, one that places importance on the results (costs and effectiveness) of health policies and promotes collaborative problem solving.

Fourth, shared health governance argues for equal access to high-quality care and expanded health agency. Individuals, providers, and institutions should share responsibilities in achieving health goals. Fifth, shared health governance requires universal health insurance coverage via shared costs and risk pooling, with health care funded through community-rating and progressive financing.

Sixth, evaluations of health policies and technologies must consider costs. Every resource has an alternative use, so its expenditure represents an opportunity cost. Individuals and society must use resources parsimoniously by evaluating the efficiency of those resources. Finally, this paradigm aims to protect disabled people from discrimination while limiting exorbitantly costly care that would deprive others of health resources.

**EQUITABLE ACCESS TO HIGH-QUALITY HEALTH CARE**

Health systems must offer individuals the prerequisites for a healthy life. Many health determinants reside outside the health care system, but those that reside within should be distributed equitably and should conform to high-quality standards. Society, through the government, should guarantee equal access to appropriate preventive measures and high-quality treatments to the extent possible. The shared health governance paradigm evaluates the impact of health care on individuals’ health capability. It assesses health capability by examining health needs, health agency, and health norms.

This approach to equal access builds on Aristotle’s principle of just distribution, according to which like cases should be treated similarly and unlike cases differently, in proportion to their difference. This account is primarily based on need. It proposes measuring the quality of health care by its ability to address functional impairments arising from injury or illness.

This principle departs from approaches that emphasize a “decency minimum” or “adequate level” of care. It implies that people with the same health needs might require different levels of resources to ensure the same capability to achieve a given health state. The argument for a decent minimum or adequate level of health care typically asserts “a government obligation to meet the basic health needs of all citizens, at least an obligation to function as a last resort.”

The result is generally 2 tiers of health care, one involving “enforced social coverage for basic and catastrophic health needs” and the other permitting “voluntary private coverage for other health needs and desires.”

Within the paradigm presented here, tiered health care is unjust because the reduced quality of the lower tier undermines some individuals’ health capability.

Adherence to this quality principle should reduce barriers to effective, efficient, and timely health care. Even if society guarantees equal access to high-quality health care, however, individuals must exercise their health agency to translate these resources into maximal levels of health functioning. Health agency includes health knowledge, effective decision making in health matters, and self-management and self-regulation skills, among many important qualities.

**EQUITABLE AND EFFICIENT HEALTH FINANCING AND INSURANCE**

Universal health insurance coverage is important to this paradigm for several reasons. Lack of health insurance is one of the primary economic barriers to high-quality health care. Resource allocation should be based on medical necessity and appropriateness rather than ability to pay. In addition, the costs of health care can both...
inhibit demand for necessary care and increase consumption of unnecessary care. Finally, the risk pooling inherent in insurance becomes central to health care financing as a result of the uncertainty of health needs, catastrophic medical care costs, individuals’ risk-averse nature, and the need to redistribute resources.21

Universal health insurance requires redistribution through taxation, and so individuals in societies providing this entitlement must voluntarily embrace higher taxes to share these costs. Health policy should ensure provision of continuous universal health insurance, including all individuals at all times, regardless of changes in income, employment, or marital or health status. This goal is achievable through pooling risks and providing community-rated insurance premiums, sliding-scale prepayments, and progressive health care payments tied to income. Direct out-of-pocket expenses, which can impede individuals in seeking necessary health care and discriminate against the sick,29 are undesirable.

Financial arrangements affect access to care and health outcomes. For example, rates of health care use are more likely to be low among uninsured Americans than among privately insured individuals. In addition, those lacking insurance are more likely to experience inadequate care and adverse health outcomes and are less likely to have a usual source of care, to visit a physician, or to be hospitalized.

Lack of insurance and high costs also cause impoverishment. A study of uninsured Americans showed that medical payments drain savings and plunge people into debt. Seventy-nine percent of the participants in that study reported that they were unable to cover basic living expenses at some point while they were uninsured.30[31]

To distribute the health care burden equitably, governments must ensure that the financial risks of illness are spread fairly across the population. Health risks and costs are difficult to predict. Insurance collectively reduces financial risk; the larger the risk pool, the greater the redistribution from healthy to sick and from rich to poor. In general, public insurance tends to spread risk most efficiently and enhance equity, assuming that taxes are progressive.31 Private insurance pools risk to some extent but also segments risk to maximize profits. Regulation must ensure that private health insurers maximize the social benefits of risk pooling and include individuals with disabilities or preexisting conditions.

Health care financing must be efficient to allow wise use of limited resources. Wasted resources lead to important health needs being unmet. Administrative costs in the United States are wasteful, accounting for as much as 24% of total health care spending, in contrast to Canada’s 11%.32 To achieve both administrative and technical efficiency,23 the health system must minimize the costs of collecting and distributing revenue and loss of funds to corruption and fraud.

A JOINT SCIENTIFIC AND DELIBERATIVE APPROACH

Reasoned Consensus Through Scientific and Deliberative Processes

Shared health governance emphasizes deliberative public policy and reasoned consensus for setting values and priorities when policy choices are difficult. It is consistent with Aristotle’s argument for ethical as well as engineering forms of reasoning6 and contrasts with both a strictly technocratic or engineering approach and a strictly procedural approach to collective choice. As mentioned earlier, it differs from attempts to develop a decision-making process that sets “fair limits” on health care in that it promotes consensus on substantive—especially scientific—principles for distribution. It offers incompletely theorized agreements to achieve consensus, in contrast to aggregate tools such as strict majority votes.

Shared health governance particularly values the agency of individuals, who, as members of the public, should have a role in political, social, and economic choice.33 Participation and open dialogue are critical.22

Public policy cannot result from narrow technical blueprints. Rather, it should emerge from a stepwise process that reflects the judgments of individuals and experts and incorporates scientific evidence to evaluate health policies, updated continually to reflect changes in medical knowledge, technology, and costs. New circumstances should lead to modifications of the ethical and scientific rules that form the basis for defining benefits packages, determining resource allocation, and constructing general guidelines. The underlying reasoning should be explicit and public and should include an appeals mechanism for reevaluating decisions.

Combining Technical and Ethical Rationality

The precise combination of technical and ethical rationalities in collective choice will vary. For example, decisionmaking at the national level requires participation by representative groups (legislatures or councils) and entails trade-offs between health and other social policies. Decisionmaking about a benefits package will focus more on broad categories at the middle level, and specific treatment decisions will engage patients and providers at the micro level. My goal here is not to specify procedures for every circumstance; however, I discuss certain substantive and procedural aspects of the process. Shared health governance emphasizes both clinical and economic analyses for evidence-based decisionmaking. The deliberative components of the process transcend the existing literature in that technical rationality, incomplete theorization, and partial ordering (e.g., allowing prioritization to take place among certain factors without ordering others) are used to establish consensus amid pluralism and wide disagreement.35

Determining a Benefits Package

What health goods and services should constitute a standard
benefits package guaranteed to all? Under this approach, goods and services that are “medically appropriate” (a term that encompasses medical necessity) to ensure central health capabilities would form the basis of a guaranteed benefits package. Society could then expand the package through reasoned consensus if so desired and resources allow. Thus, the government-guaranteed benefits package would cover appropriate and necessary care to prevent, diagnose, or treat illness, disease, injury, disability, or other medical conditions associated with avoidable morbidity or premature mortality.3,5

A major difference between this account and others is its requirement that goods and services be medically appropriate as well as medically necessary. Adding medical appropriateness and established clinical practice guidelines to the medical necessity standard introduces another level of science-based prioritization. Shared health governance gives authority back to physicians and patients, allowing them to make informed judgments about resource allocation on a category-by-category and case-by-case basis.

Not all health care is medically necessary or appropriate. Many advanced medical technologies are only marginally effective, extending life a few weeks or months, for example. Moreover, although millions of people in the world receive appropriately delivered, high-quality health care, many others endure, overuse, or misuse health care services. According to some estimates, up to 30% of all US health care goes to waste through clinical practice inefficiencies.34 Eliminating inappropriate and unnecessary interventions is the first step to establishing equitable access to high-quality care and lowering costs.

Well-established, evidence-based clinical guidelines, continually updated and improved on the basis of new medical information, systematically bring together experience and evidence on various conditions and can guide treatment. However, clinical guidelines alone cannot reduce differences in health care quality, nor can they evaluate medical technologies. Although there is no perfect formula for determining whether interventions are appropriate and necessary, certain process components can combine in a workable health policy decisionmaking model.

At least one example of some of the elements of such a process exists. The Rand–UCLA (University of California, Los Angeles) appropriateness method35(p59) combines substantive criteria with procedural mechanisms that incorporate expert medical judgments, patient input, and scientific evidence to generate publicly available medical guidelines and standards for guiding policy decisions. Its three criteria for evaluating health interventions are (1) duration and degree of improvement, (2) likelihood of a beneficial outcome, and (3) associated risks. A multispecialty panel of physicians makes recommendations on medically appropriate procedures based on the criteria just mentioned and professional clinical practice guidelines. Patients have input after physicians assess an intervention’s effectiveness.

An intervention is deemed necessary if it is medically appropriate (expected medical benefit to the patient exceeds expected health risks)35 and if “withholding the procedure would be deleterious to the patient’s health.”36(p357) The process includes tallying of costs but not incorporation of costs into appropriateness rankings.35,37 As a means of protecting people with rare conditions, the process does not include a calculation of the number of individuals benefiting from the intervention.

Recommendations rest on up-to-date, published, evidence-based research.38 When evidence is incomplete or inconsistent, recommendations reflect the physician panel’s judgment. The process can help determine a benefits package and assists decisionmaking among individuals. For example, the panel might recommend a hysterectomy for women who have attempted alternative treatments (e.g., for pain or bleeding) without success but might not recommend the procedure for women with first-degree uterine prolapse that does not involve incontinence or pain.39 Or it might rule against postdischarge coronary angiography for myocardial infarction patients who do not have angina or have not undergone an exercise tolerance test.40 This process could be applied to new technologies, pharmaceuticals, and treatments as well as existing ones.

**Protecting Individuals With Disabilities and Handling Difficult Cases**

Some ethical theories focused on yielding the greatest net social benefit appear discriminatory.43–45 Critics charge these approaches with neglecting the individuals most in need, especially those with disabilities44,46–48 and those with rare conditions.49 Patients with severe disabilities must be protected from unfair discrimination; at the same time, however, society must allocate scarce resources as efficiently as possible. An
especially difficult issue is what some have called the “bottomless pit objection,” whereby individuals or small groups use large proportions of resources for unlimited periods.\textsuperscript{50,51} Rawls’s “maximin” or difference principle and the fair equality of opportunity (FEO) account have encountered particular criticism.\textsuperscript{51} The “reasonable accommodation” principle outlined in the Americans with Disabilities Act and the Rehabilitation Act\textsuperscript{52,53} provides guidance here.

Reasonable accommodations are non-“fundamental” alterations that can be undertaken without causing “undue hardship” to a program (e.g., related to employment, public service, public accommodation, and telecommunication). The Americans with Disabilities Act defines undue hardship as “an action requiring significant difficulty or expense.”\textsuperscript{52} The Equal Employment Opportunity Commission assesses hardship by considering the “nature and cost” of the accommodation and the impact on the “overall financial resources” of the organization involved. The commission’s guidelines specifically disavow the use of cost–benefit techniques.\textsuperscript{54} Applying rigid cost–benefit analysis to interventions for the disabled would be discriminatory, some critics argue, because some individuals with disabilities would receive less objective benefits relative to costs than would individuals without disabilities.\textsuperscript{52}

Several points require emphasis in analyzing how the Americans with Disabilities Act and the Rehabilitation Act could apply to resource allocations. First, when defining a benefits package, both private and public actors must not discriminate in assessing medical appropriateness and necessity. Second, these assessments should distinguish between the minimum level of functioning and a potentially achievable level, and the benefits package should target the potentially achievable level. This ensures that the weight assigned to health benefits for individuals with disabilities is equal to that assigned to benefits for individuals without disabilities.

Third, appropriateness and necessity criteria should not discriminate against individuals with rare conditions. That is, preventive measures or treatments that confer a large benefit on a few people should be included in a benefits package. One example would be timely treatment (within 24 hours of birth) for maple syrup urine disease, which affects 1 in 225,000 births.\textsuperscript{55} Fourth, clear examples of discrimination, such as limiting hospital days without considering condition severity, should be considered unethical because they exclude those with more-severe or -complicated primary and secondary conditions, reducing their ability to benefit fully from an intervention.

Fifth, benefits should not include extremely costly care that offers little improvement or is medically futile, including life support for permanently unconscious patients. Determining the appropriateness of medical care will help illuminate specific cases of medical futility. If patients or their families have previously specified that patients wish to avoid futile care (e.g., through advance directives or do not resuscitate orders), their wishes should be met.\textsuperscript{56,57}

Finally, with respect to disabled individuals, who may receive reduced benefits relative to costs, this account weighs absolute harm in terms of functioning capability rather than through the use of a strict cost–benefit analysis.\textsuperscript{49} In operationalizing these ethical principles, however, it is appropriate to consider the absolute costs of certain treatment protocols and their effects on overall health system resources (as discussed subsequently).

Combining the principles of reasonable accommodation, medical appropriateness, and medical necessity will help society to clarify its obligations and will help obviate problems such as the “bottomless pit.”\textsuperscript{50,51} Existing case law could reveal the rationale and application of such a standard. Eventually, however, decision-making in this area may be guided by a body of case law (as developed elsewhere)\textsuperscript{57,58} and policy case studies in health resource allocation.

**Incorporating Efficiency Through Joint Clinical and Economic Solutions**

Efficiency goals should, however, temper equality goals. Although it is consistent with the focus of welfare economics on efficiency, the shared health governance paradigm differs in that it applies efficiency principles to equity goals. Meeting the dual social obligations of equality and efficiency in health system reform requires both clinical and economic solutions. However, clinical input must drive this process to ensure that physicians and patients are the primary determinants of care.

Still, successful implementation of effective clinical solutions requires economic incentives. Empirical evidence suggests that economic tools can influence the behavior of patients, physicians, and planners. Several measures have encouraged cost consciousness and efficiency.

On the demand side, instruments such as copayment schemes and health insurance deductibles sensitize consumers to health care’s cost and deter consumption.\textsuperscript{59} On the supply side, price, budgetary, and salary incentives (prospective and capitated payment schemes, global budgets, competition,\textsuperscript{60} and utilization and management review systems) are used in attempts to reduce costs. In theory, these incentives force physicians and hospitals to provide only the most cost-effective care. In some cases, they actually shift the financial risk of health expenditures from insurers to providers. Payment mechanisms (e.g., diagnostic-related groups) and health financing and delivery institutions (e.g., health maintenance organizations and managed care organizations) have resulted from these efforts.\textsuperscript{61} However, whether these measures have actually reduced expenditures or improved efficiency is unclear.\textsuperscript{62,63}

Such strategies could reduce the volume of health care provided. However, they frequently reduce levels of both inappropriate and appropriate care, resulting in detrimental health consequences, particularly for the poor and...
medically indigent, who often have the greatest health care needs and respond most sensitively to consumption-deterring incentives.\textsuperscript{64} Therefore, under this paradigm, economic solutions follow and complement clinical progress, not vice versa. Training physicians by rewarding appropriate care and penalizing inappropriate care should receive particular attention.

Fair health system reform must consider costs, and there are several methods of doing so. First, developing and implementing appropriateness guidelines will improve health care quality, reduce health care quantity, and decrease overall costs. Avoiding inappropriate coronary angiography after a myocardial infarction, for example, could save more than $700 million annually.\textsuperscript{40,65} Furthermore, using appropriateness guidelines should reduce cost-ineffective care.

In one study focusing on post–myocardial infarction angiography, an expert panel’s appropriateness ratings were compared with cost-effectiveness ratings derived from a decision-analytic model. The clinical scenarios considered appropriate by the expert panel were more cost-effective (average of $27 000 per quality-adjusted life-year gained) than those deemed inappropriate (average of $54 000 per quality-adjusted life-year gained).\textsuperscript{66} Used in this manner, cost-effectiveness analysis can be helpful in comparing trade-offs between costs and effectiveness.

Second, efforts to further reduce inappropriate care should involve financial incentives based on quality rather than quantity. As information on inappropriate care accumulates, economists and health policy analysts can create policy instruments\textsuperscript{67} to reward appropriate care, necessary care, and risk adjustment. For example, health plans and hospitals could reap rewards for lower mortality in the case of certain procedures. Because it has been shown that financial incentives influence physicians and patients, efforts to motivate high-quality, appropriate care could be effective. Efforts are under way to pay providers for performance,\textsuperscript{68} although there are concerns with this approach.

Third, efforts to reduce health care costs are essential. In addition to economic incentives for influencing participants’ behavior, macro-level efficiency evaluations should inform guidelines for maximizing resource efficiency. Cost-minimization analysis\textsuperscript{69} is a form of efficiency evaluation that assumes a given objective (e.g., level of effectiveness) and searches for the least costly method of achieving it. One such analysis showed that although peripheral blood progenitor cell transplantation and autologous bone marrow transplantation are equally effective in treating Hodgkin’s and non-Hodgkin’s lymphoma, the latter costs $14 000 more than the former.\textsuperscript{70}

Cost-minimization analysis is being used in several medical fields, including obstetrics and gynecology,\textsuperscript{71,72} cancer therapy,\textsuperscript{73} stroke rehabilitation,\textsuperscript{74} and ambulatory anesthesia.\textsuperscript{75} It has also highlighted potential savings in pharmaceuticals. This approach differs from other efforts to address the efficiency–equity trade-off.\textsuperscript{76–78}

Volume purchasing, restricted networks, and reductions in non-patient care costs could also reduce expenditures. Further work in this area could reveal ways to reduce total health care costs without compromising quality.\textsuperscript{67} Moreover, studies of cost differences between for-profit and nonprofit providers and insurers\textsuperscript{79} offer evidence of cost reductions, as do studies of efforts to reduce costs near the end of life.\textsuperscript{80}

Finally, improved information systems could help standardize medicine and provide physicians and patients with the essential evidence base for appropriate and necessary care. Reporting of annual data on risk-adjusted mortality after coronary artery bypass graft surgery in New York, for example, resulted in a 41% decrease in mortality between 1989 and 1992.\textsuperscript{81} Streamlined data systems also help reduce unnecessary administrative costs.

**IMPROVED HEALTH SYSTEM EFFICIENCY OR MORE EXPENSIVE CARE**

The shared health governance paradigm does not propose a simple formula for answering complex questions; rather, it outlines several key ethical principles for guiding health care reform and policy. Although no method of health system reform can satisfy all ethical requirements, policies derived under this framework will more fairly distribute the benefits, burdens, and costs of ensuring equal access, providing universal and comprehensive coverage.

If greater health system efficiency is achieved but health care costs continue to rise, the American public must decide whether it is willing to spend more on health care. Most health economists find this stage of decisionmaking straightforward because they believe individuals should be free to spend what they like on goods they value highly, provided that waste is eliminated. Recent studies suggest that Americans’ willingness to pay for health care far exceeds current and even projected costs of medical goods and services.\textsuperscript{82} Although the shared health governance approach seeks to make more-efficient use of the existing level of health resources, it will not produce a flawlessly efficient health care system, given the number of organizational, institutional, and political obstacles likely to impede its implementation.

There will be reasonable objections to this paradigm. Some critics will argue that society is unable to afford such a generous plan and will demand more assurance of cost containment. Physicians might object, regarding clinical guidelines as “cookbook medicine” or a “liability,” even though such guidelines are designed to assist policy and clinical decisionmaking rather than replace clinical judgments. Despite these objections, this framework has many advantages and is perhaps our best hope for replacing the current system, with its exorbitant costs, widespread waste, and pervasive injustice.

**About the Author**

Jennifer Prah Ruger is with the School of Medicine, Graduate School of Arts and Sciences, and Law School, Yale University, New Haven, CT.
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