CHALLENGES FOR THE PUBLIC IN NEGOTIATING THE HEALTH SYSTEM IN THE 21ST CENTURY

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ABSTRACT This paper addresses the challenges and opportunities that face the public in negotiating the health care system (both medicine and public health) in the 21st century. It addresses three issues: how consumers exercise choice, with special attention to the choice of health care coverage; how patients and communities interact with clinicians and public health professionals; and whether and how the public's "voice" is heard as health policy decisions, at the societal and institutional levels, are made. With respect to each of these issues, the paper describes the current status of public influence and articulates a vision for the future. These three related visions are (1) that empowered, informed, supported consumers make decisions about health plans, clinicians, treatments, and their own behavior; (2) that clinicians and public health professionals, working as partners with patients and communities, are in a position to "standardize the customization of care" so that all aspects of care are tailored to the needs of the individual, family, or community in question and social, economic, and cultural factors are taken into account in the day-to-day practice of medicine and public health; and (3) that the ability and willingness of the public to negotiate and shape the health care environment is supported by an independent infrastructure that permits enhanced public involvement in health policy making and governance. The paper identifies key elements of this vision, discusses challenges to pursuing and achieving each vision, and identifies opportunities that may support the pursuit of the vision.

Lest we forget, and Martin Cherkasky did not, the health system exists to serve the needs of the public. The ultimate criterion for judging the effectiveness of the health system (including both medicine and public health) is whether it improves the health of individuals and populations. As we approach the millennium, our health system is in transition, even in turmoil. The question is not whether change will come, but whether the net result of multiple changes, many discussed in this conference, will be to increase, decrease, or have no discernible effect on the health of the public.

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The fundamental assumption of this paper is that the health system cannot be effective unless the public participates, far more than is common today, in shaping it. Recent changes, especially the growth of managed care, have given rise to serious concerns about the ability of people to find their way through the maze of health care toward the goal of health improvement, or at least maintenance. We must ask ourselves, however, whether or not the health system has ever been "user friendly." In the midst of today's turmoil, we must do more than protect the narrow pathways that already help the public shape the health system and their health. We must blaze new and wider trails to that destination and mark them clearly so they can and will be used. For that reason, this paper will address not only the challenges facing the public in negotiating the health system of the future, but also the opportunities for improving the public's ability not only to negotiate, but also to shape, the system.

The paper addresses three related issues: the choices made by individual consumers and patients, especially their choice of health care coverage; the relationship between those getting care or services and those providing those services; and last, but not least, how policy decisions are made in and about the health care system. To begin, the paper briefly reviews our current situation with respect to these three issues.

WHO EXERCISES CHOICE TODAY?

A number of choices that conceivably could be made by individuals have the potential for significantly affecting their health care and their health. These include the choice of a health care coverage option or health plan; the choice of health professionals, institutions, and programs; the choice of interventions; and the choice of personal behaviors. While all are important and related, we focus on the choice of health plan. Who makes health care coverage choices today? One group does not: the 43 million Americans who have no coverage.¹ Of those with employment-based coverage, a recent Kaiser Family Foundation survey found that about half are offered a choice of health plan.¹ Medicare beneficiaries have choices already with respect to the type of coverage (Medicare alone; Medicare with a supplement; and, in many but not all places, a Medicare health maintenance organization [HMO]). The 85% of beneficiaries who are not in an HMO also have a wide choice of providers. Those covered through Medicaid have options, but the extent of their options depends on whether the particular state has chosen to go in the direction of mandatory managed care. Even under those circumstances, however, the beneficiary has more than one managed-care

plan from which to choose. Medicaid beneficiaries not in managed care typically can choose their individual providers, except that in states with low reimbursement rates, many providers do not accept their coverage.

It can be argued that those who purchase health care coverage on behalf of their employees, retirees, or public program beneficiaries are the ones making the most significant health care coverage choices today.² They screen, to a greater or lesser extent, the options that will be offered and typically determine the terms on which they will be offered.

Purchasers, including major players like the Medicare program, are beginning to insist on the collection of data from health plan members that report on and assess their experiences in their plan. For example, Medicare, several state Medicaid programs, and some private and public sector employers have implemented the Consumer Assessment of Health Plans (CAHPS) surveys to gather such data. A version of the CAHPS survey is also a major source of data for the Health Employer Data and Information System and therefore is administered to members by many additional HMOs. We as yet know little about whether the results of these quite recent survey efforts (which were designed primarily to provide feedback to consumers from consumers³) are taken seriously by purchasers when they make decisions about which plans to offer to their employees. Research is under way to track these effects.

Even when consumers have an apparent choice of plan, however, they may not have a real choice because of financial or geographic barriers to one or more of the options available. In addition, consumers today are seriously hampered, in most cases, by the lack of useful information and assistance to support their decision.⁴⁻⁸ It has long been noted that consumers know little about their health care coverage.⁹ In the context of the growth of managed care, recent evidence indicates they do not understand the most consequential features that distinguish types of coverage⁴ and have little understanding of what is at stake when they make a health plan choice, especially when it involves, as in the case of managed care, a simultaneous choice of plan and provider network.¹⁰⁻¹² The information they get about health plan choices typically covers premiums and out-of-pocket costs, covered benefits, and some information about how the plan works and which providers are included in the network if there is one. Until recently, little or no reliable comparative data about plan performance or quality have been available, and the information that is provided is seldom presented in a manner that facilitates comprehension and use by laypeople.

Given these circumstances, people rely on family and friends, physicians,

insurance brokers and agents, and advertising for their “information” and “decision support.”* A telling consequence of this set of circumstances can be found in the relatively high rates (estimated at about 40% nationally) at which those who are Medicaid eligible in mandatory managed-care programs fail to make any choice at all and are instead “autoenrolled” or “default enrolled” into a health plan either at random or using a formula designed by the state Medicaid agency.¹³

WHO SHAPES RELATIONSHIPS BETWEEN PATIENT AND PROVIDER TODAY?

The paucity of consumer influence in choosing health plans is reproduced (or perhaps simply reflects) in the limited impact patients have in shaping their relationships with individual and institutional providers of health services. As a society, we still are operating largely, although not entirely, under fairly traditional assumptions about patient-clinician relationships. We assume, probably correctly, that the distribution of power between an individual patient and clinician, in the clinical encounter, is unequal. We assume, less correctly, that the distribution of expertise between an individual patient and clinician is unequal. Clinicians almost always have more knowledge of their clinical specialties and of the science that underpins their specialties, but the patient is uniquely an expert on himself or herself, on his or her family, and on the social, economic, cultural, and perhaps even physical pressures he or she faces at home, at work, and in the community. The first kind of expertise is acknowledged by society and in interpersonal interactions. However, in spite of all we have learned, from Cherkasky and others, about the critical impact of social, psychological, economic, cultural, and environmental factors on the health of individuals and communities, the second kind of expertise rarely is viewed as either relevant or significant.

The assumed unequal distribution of power and expertise is related to another assumption—that the patient is vulnerable and needs protection and support. Of course, when we are sick, we are vulnerable; we do need support; we may well need protection, and we value those who provide it. The vulnerability of patients, their need for protection and support, leads to another assumption: that patients can and should trust their physicians or other clinicians to act in their own best interests. As a society, we jettison the assumption that patients can trust their clinicians at our peril,¹⁴⁻¹⁶ but what if an individual clinician is not

*It should be emphasized that we, as a society, are making political choices that result in the lack of universal coverage; but those without the coverage do not seem to have a meaningful voice in the periodic debates.

trustworthy? What if the clinician is not acting in the patient's best interest, but rather compromising that interest because of financial or professional pressures or because of personal problems? What are the dangers in maintaining what is now an illusion at the individual level in order to maintain our assumption at the professional and societal level?

WHO MAKES POLICY DECISIONS?

Myriad decisions are made that significantly influence the health care system and the health of the public. From a social medicine perspective, many of the most important decisions that affect the health of the public are made outside the health sector. Often, such decisions (e.g., about welfare, education, housing, or immigration policy; about transportation systems, economic development and job development and training, law enforcement) are made with little or no input from those who might be able to articulate the consequences for health of options under consideration. Even within the health care system, who is making the critical policy decisions? What is the influence of the public on these policy decisions?

In the public sector, in which we would expect to see the greatest public influence, many important decisions are made by elected officials and by officials appointed by elected officials. It is rare that health rises high enough on the political agenda to permit us to say that the public's concerns about health issues are reflected in elections. Nevertheless, the public does have the capacity to express a "voice" to elected and appointed officials between elections. The politics of health care and the policy-making process in health care, however, are dominated by the interplay of interest groups such as clinicians, hospitals, purchasers of health benefits, malpractice attorneys, insurers, and the like. The voice of the consumer is not heard very often, or very loudly, in the land.

In fact, there is little or no infrastructure to support the expression of voice by consumers and patients.¹⁷ Perhaps as a consequence, elected officials often depend on the results of polls and focus groups to gauge both the direction and the intensity of public opinion on various issues. Especially during the 1990s, politicians frequently have espoused positions that appear to be "hot buttons" with the voting public. Examples include recent attention to the need for patient protections against HMOs and the periodic need to "protect" the Medicare program from looming financial collapse. It can be argued, however, that these politics are "symbolic,"¹⁸ and that the exact nature of these protections is driven by interest groups and ideological commitments. The 1997 Balanced Budget Act, for example, legislated a set of changes in the Medicare program that are perhaps

the most sweeping, for beneficiaries themselves, than any enacted since the program began.¹⁹ There was little public debate on the details of these changes, there has been little coverage of them in the press, and there is little knowledge of them among beneficiaries.

There are, of course, exceptions to the statement that there is no infrastructure (in particular, no interest group structure) that serves as an expression of public or consumer voice. The most prominent exception is probably the American Association of Retired Persons, with members that are more likely to have concerns about their health, are more likely to vote, and are more likely to feel entitled to health care coverage and quality health care. Other exceptions include disease-specific organizations such as the American Lung Association, the Alzheimer's Association, or the American Cancer Society. Such organizations claim to represent patients and their families, but they also are influenced significantly by providers and researchers who deal with specific diseases and, of late, by pharmaceutical companies. It is truly exceptional when those affected by a particular disease become more aggressive in voicing their desire not only for more response from government and the health care system, but also for more influence over policy decisions at the macrolevel and treatment decisions at the microlevel. Two examples come to mind: people with disabilities and their families and those initially affected by human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS).

Perhaps recognizing this situation, government agencies frequently mandate the involvement of affected populations in policy decisions through the mechanism of advisory groups, planning councils and similar bodies. There has been little systematic research about the extent to which these mechanisms have a discernible effect on decisions. My own early research on health planning agencies, for which there was a mandate that at least 51% of governing bodies be "consumers" (defined primarily as nonproviders), indicates that the numerical majority of a group of unpaid individuals, rarely linked to a well-organized constituency and rarely provided by significant technical support, were rarely a match for paid representatives of provider organizations and associations, health plans, and employers.²⁰

What of the private sector? The picture is not much brighter. In the not-for-profit sector, decisions are made by boards of trustees typically chosen for their expertise, their wealth, or their links to powerful community constituencies. There is a clear recognition of the need for community participation on the governing boards of hospitals, but there is little evidence that such participation changes the decision-making dynamics. Furthermore, as community hospitals

become parts of vertically and horizontally integrated systems, considerable authority is vested in the system-level board, which research indicates is far more likely to take a "corporate" form: smaller, more dominated by people with substantial technical expertise.²¹

In the for-profit sector, such corporate boards are the norm. Further, the attention of the board, and the management, is shaped significantly by the capital markets, which would be concerned about the public only to the extent that the response of the public to investor-owned institutions might have discernible financial consequences. These stresses are felt in not-for-profit institutions as well. Their bond ratings and ability to borrow funds for capital improvements also depend on their ability to demonstrate financial margins of 6% to 8%.

IS THE STATUS QUO ETERNAL?

In sum, as we approach the end of this millennium, it does not appear that the public, individually and severally, are in a strong position to make important choices in their own best interests, to shape their interactions with those who provide them with care, and to influence public and private policies that in turn influence what happens in and to the health care system. Are we at an impasse? Is this situation immutable? I believe it is not, that there are signs of change and potential change that give cause for guarded optimism.

First, the baby boom generation is just entering the stage of life at which health issues and health care become more salient. Known for making demands and taught to "question authority," this group is less likely to put up with being ignored by health professionals and policymakers. Second, perhaps in parallel to a broader societal emphasis on businesses being "customer driven," health care organizations and professionals are beginning to pay more attention to customer satisfaction and customer service. Third, existing powerful interest groups in health politics are starting to couch their demands in terms of the needs and concerns of consumers and patients. For example, the real revolution in health care in the 1990s may well be that we now believe that health care organizations should be "accountable." These ideas have been put forward primarily by purchasers, both public and private, but accountability is presented as being to the public and to the consumer/patient/customer. This dynamic can also be seen in the politics surrounding passage of a spate of patient protection laws at the federal level, but more especially at the state level. For example, the federal law requiring health plans to permit women to remain in the hospital for at least 48 hours after normal delivery of a child was promoted as protecting the rights of women and babies, but was lobbied for by obstetricians, pediatri-

cians, nurses, and other clinicians. It is not surprising that laws are passed because of lobbying by professional associations; it is somewhat novel that the "banner" being used is the protection of patients.

A VISION FOR THE FUTURE OF CONSUMER CHOICE

Let us return now to a discussion of the challenges and opportunities for the public in negotiating and shaping the health system in the 21st century. To begin, I propose a vision for the future for consumer choice, which will be applied initially to choice of health care coverage. The vision is that empowered, informed, supported consumers make decisions about health plans, clinicians, treatments, and their own behavior. There are four key elements of this vision; if these elements are not in place, it probably cannot be said that the influence of consumers on their coverage and on the health care system will have been enhanced:

1. Meaningful choices are available.
2. Useful information about choices and their consequences is available.
3. Individuals can choose how much involvement they want in making choices.
4. Choices made by consumers have consequences for system actors, including purchasers, plans, providers, and policymakers.

There are many challenges inherent in pursuing and reaching such a vision. At the outset, it is essential to acknowledge that there are variations in the extent to which consumers are even interested in participating actively in making health decisions, especially health care coverage decisions, in their own behalf. People need some autonomy in deciding how much autonomy they want and need. However, we do need ways to gauge, systematically, how much influence and how much information people want. Such assessments may be needed periodically since circumstances, preferences, and needs will change. Most important, however, the opportunity and supports for taking a more active role need to be in place and understood.

It is also important to recognize that increasing the number of coverage options available to people does not necessarily increase their ability to exercise meaningful choice and increase the extent of their influence. For example, many analysts and advocates are very concerned that if the full array of options that could now be offered to Medicare beneficiaries (through the Medicare + Choice provisions of the Balanced Budget Act of 1997) actually were available, consumers would be mightily confused and feel, and be, even less able to make a good

decision. In the private market for Medicare supplements, during the 1970s and 1980s, a proliferation of “choices” emerged that differed in small and often inconsequential ways designed to provide fodder for “niche marketing” strategies. The resulting confusion²² led to the partial standardization of the benefits of private supplements into 10 “types.” When policies were thus more standardized, the number of choices of benefit package went down, but it became easier for a consumer to notice that they did not have to pay \$75 a month for an “E” policy when one was available from a reputable insurer for \$60 a month.²³ Our challenge may not be to multiply the number of options, but to support the development of options with differences that are more easily apparent to a layperson.

The challenges to developing and disseminating meaningful education, information, and support for health care coverage decisions are substantial. They include

- The lack of basic knowledge among consumers about their current health care coverage, available alternative kinds of coverage, the most significant distinctions between types of coverage, how coverage can affect one’s ability to access quality providers and quality care, and most fundamentally, how the health care system works. This basic knowledge is viewed by consumer researchers as essential as a foundation for understanding choice and using comparative information to support choice.⁴⁻¹²
- The multiple dimensions of health care and coverage that have potential relevance to decisions.^{7,8}
- The known limits of most people with respect to the cognitive processing of information (e.g., people can typically keep only five to seven concepts in short-term memory at a time when many more dimensions and data points may be relevant to a health care coverage decision).^{5,6}
- The inherent cognitive complexity of making comparisons even on a single dimension given problems with both literacy and numeracy in the American population.
- The lack of clarity, among most consumers, of which dimensions of coverage and health care are most important to them.
- The potential need to make trade-offs between dimensions that are of similar importance.
- Perhaps most important, the significant shortfalls with respect to an infrastructure of trained professionals and/or volunteers to provide some level of personal assistance in correctly interpreting comparative information and applying it to the circumstances facing particular individuals.²⁴

One challenge is missing from this list that would have been there 2 or 3 years ago: the absence of useful comparison information. We currently are going through a period of rapid increase in the amount of information that conceivably could be available to support such decisions. In a sense, after years of information drought, consumers may be facing an information deluge. We by no means have all the information (or even the most important information) needed to support decisions, but we certainly have a start, and more is on the way. More measures are being developed. Existing measures are being vetted, and some then are being blessed, for example, for inclusion in the increasingly influential Health Employer Data and Information Set. A new generation of consumer satisfaction surveys is being created that is designed specifically to provide feedback to consumers (the CAHPS surveys discussed above). The considerable efforts now under way to find ways to present this comparative quality information to consumers have helped uncover both effective strategies and complex dilemmas. The work on quality measurement development and the presentation of comparative quality information is just beginning, but it has at least begun.

The next phase of the work must also address a highly significant challenge for creating an environment in which meaningful choice is possible: the need to tailor the content and presentation of information, and the channels and media used to disseminate it, to different target groups and ultimately to different individuals. In our work, for example, we have found that educational level, health status (in particular, whether or not the individual has a pre-existing diagnosis), and the related factor of age all have a significant impact on whether and when information is salient, comprehensible, usable, and considered trustworthy. For example, if people do not have a specific condition, they are quite a bit less interested in information on how a health plan performs in taking care of that condition.¹² If they do have a condition, they sometimes want to know only about how people "like them" (i.e., with the same condition) respond to health plans.

People who are sick are naturally very interested in how well plans do at taking care of people who are sick. This leads, however, to the next challenge to creating meaningful choice and meaningful information for consumers: the disincentives that now exist with respect to serving those who need the most health care because premiums are not significantly risk adjusted. For example, people with disabilities and chronic conditions may well be best served by a health care plan that is capable of genuinely managing and improving care and that might even "specialize" in serving the needs of this population. Absent risk-adjusted payments, however, such a business strategy is suicidal. Even more

broadly, those who are well today, but who also realize they or someone in their family someday may need significant services might want to know how well different plans perform in taking care of the sickest patients, rather than how they take care of the "average," generally healthy members. Currently, however, a plan that did well in taking care of the sickest patients would not want it publicized.

These challenges are considerable. There are, however, opportunities that can be used to meet them. The increasing pressures for accountability on the part of the health care system have provided and will continue to provide an environment in which it is far easier to develop useful comparative information on various options. It must be acknowledged that this has been facilitated by the development of health plans that provide an organizational focal point for accountability and data collection that is sadly lacking in the purely fee for service environment.

There is a growing realization, in addition, that consumers and patients are in an excellent position to provide information on health plan quality that cannot be gathered as easily or appropriately from other sources.²⁵ The database for informed consumer choice is growing. Research is under way (although more is needed) on how to translate the availability of information into opportunities for meaningful choice. Perhaps most important, our technology is exploding in ways that will facilitate both data collection and information transfer in both directions. People already use the World Wide Web extensively to get health-related information.^{26,27} Products are being developed that use computers in various ways (free-standing kiosks with touch screens, Web sites, interactive videos, etc.) to facilitate both information dissemination and decision making. As the number of people who are comfortable with this technology grows, it can become an important element in fulfilling the vision of empowered and informed consumers.²⁸ Of course, the very facility provided by such technology also raises the need for thoughtful analysis of whether and how to protect consumers from misinformation and exploitation in this as in other contexts.

A VISION FOR THE FUTURE OF RESPONSIVE CARE

I propose a vision of the future relationship between patients and the health care delivery system, especially clinicians. In this vision, clinicians and public health professionals, working as partners with patients and communities, are in a position to "standardize the customization of care." What this means is that systems are in place to ensure that, as a regular matter, all aspects of care are tailored to the needs of the individual, family, or community in question. In particular, this

vision involves taking social, economic, and cultural factors into account in the day-to-day practice of medicine and public health, that is, taking what we know from inquiry into social medicine and putting it into practice.

There are several key elements of this vision. First, it builds on the foundation laid out earlier, the foundation of meaningful consumer and patient choice of health plan, health providers, and treatments. Second, patients, families, and communities are partners with clinicians and public health professionals in the prevention, diagnosis, treatment, and management of individual and community health problems. Third, there is an evidence base to inform the selection of interventions not just in terms of the nature of the health problem in question, but in terms of the particular characteristics and circumstances of individuals and communities. Fourth, health professionals are trained to be competent in applying this evidence base, that is, in matching interventions to individual and community characteristics. Finally, in all aspects of interactions with patients and communities, there is a recognition of the role played by non-health sectors (e.g., education, housing, workplace) and an ability and willingness to forge linkages with these sectors as part of the process of addressing and taking into account social, economic, and cultural factors.

Perhaps our greatest challenge in achieving this vision is the partial nature of our understanding of how exactly to take social, economic, and cultural factors into consideration in our interactions at the “microlevel” of particular individuals and communities. This challenge is amplified by the increasing cultural diversity of our nation. In my interactions with health professionals, one common response to the clear evidence of the impact of such factors is that there is nothing to be done about them. Acknowledging that there is, for example, a strong relationship between education or income and health status, they appear paralyzed in terms of doing anything about the educational levels or incomes of their individual or community clients. My own training in public health included a strong dose of the notion that public health and social justice were part of the same agenda. But, it will take considerable time and effort to address deep-seated social and economic factors. We must ask ourselves, what is to be done in the meantime? The answer proposed here is that, even while working on the amelioration or elimination of negative social factors, we must work harder at taking those factors into account in designing and implementing interventions.* We need

*It may be especially important to take these factors into account as we allocate resources for both medicine and public health programs.

more systematic evidence of just how to do that, and to get the attention of policymakers, we also need evidence that tailoring of this kind is ultimately not only more health effective, but also more cost effective. Much recent health services research has been a reaction to high levels of "variation" in clinical practice from one community to another, which appear to be explained primarily by variations in the capacity to provide certain services or in locality-specific norms of appropriate physician practice.^{29,30} To some extent, our understandable efforts in response to these variations (i.e., specifying clinical practice guidelines, disease management protocols, and "best practices") reveal an obsession with consistency that may not be compatible ultimately with true effectiveness, especially in reducing disparities in health experiences and outcomes for those who do not look like the "average" patient or community.

There are also challenges to achieving true partnerships between patients and clinicians and between communities and professionals. One such challenge is the ambivalence of all the parties involved to changing both familiar patterns of interaction and assumptions about roles and responsibilities. For example, a partnership relationship implies that both parties eschew passivity. This means that clinicians and professionals reach out to learn about and engage individuals and communities and find out their questions, priorities, and preferences. It means also that individuals and communities take the initiative in making their needs, concerns, and characteristics known; actively participate in planning and taking action and in assessing its results; and take advantage of opportunities to change their circumstances. These are new roles and, perhaps as important, new responsibilities. The training of many of today's (and even tomorrow's) clinicians still is biased against such shared responsibility. It must be acknowledged that there are ethical, as well as practical, uncertainties that arise when responsibility is acknowledged to be shared rather than vested in a single party. In this context, the recent emphasis on accountability in health care may work against shared responsibility. The current conceptualization of accountability is that a single party must be held accountable for a particular process or outcome. But, as noted by a recent Institute of Medicine Committee on Using Performance Monitoring to Improve the Health of the Public,³¹ if we acknowledge that health is determined by multiple factors, shared accountability is inevitable. The key may be to find ways to make sure that all parties are contributing what they can to the desired outcomes.

The time may be ripe to pursue this vision. There is a growing recognition, probably fueled by our increasing cultural and behavioral diversity as a society,

that one size does not fit all.^{32,33} Perhaps more important, there is a growing recognition of what patients and communities can, and must, contribute for health to be improved. For decades now, it has been clear that the burden of illness in our society is fueled primarily by increases in the prevalence of chronic illnesses and the complications that arise when those illnesses are not well managed. Scientific advances have taken what used to be considered acute and fatal illnesses and transformed them into chronic conditions (e.g., HIV/AIDS). Increasingly, we recognize that patients can and should play a role in the effective management of chronic conditions, and that patient self-management leads to better outcomes.^{34,35} In terms of population health, the role of behavioral risk factors is now clear.³⁶ What is getting clearer is that attempts to alter the prevalence of behavioral risk factors have to take into account such factors as social policies and social norms (tobacco control is the best example here³⁷), that they will not succeed if they are perceived as imposed by outsiders, and that they are more likely to succeed if they engage and respond to local residents.³⁸

In addition, there is a growing research base on patient-physician relationships to support movement in the direction of more responsive care. The importance of such relationships is beginning to be emphasized in health professions training, especially in the context of more emphasis on primary care. It may also be the case that we will be in a better position to take cultural factors into account as the health workforce, especially at the upper echelons, becomes culturally more diverse.

The standardization of customized care can also be supported by improvements in information technology. Such improvements make it much more feasible for us to collect data that describe, on an ongoing basis, key characteristics of patients and communities that need to be taken into account. Such technology can serve as a kind of "extended memory" to help all members of a clinical team, for example, keep in mind the experiences and expressed preferences of individual patients and family members. Technology can also be used creatively to facilitate feedback from patients, to help them get quick access to resources, and to simplify more routine interactions. The point is not to eliminate personal interactions, but rather to enhance the quality of those interactions by avoiding unnecessary repetition of data gathering and other routine tasks. There is room for improvement. On a recent medical visit, I wrote down my name, address, and phone number three times within 15 minutes at three reception desks that were no more than 50 feet apart. Apparently, the concept of multiple-copy forms, let alone computerized records, was not operational in this environment. There were, by the way, computers at each one of these stations.

A VISION FOR THE FUTURE OF PUBLIC INVOLVEMENT IN HEALTH POLICY AND GOVERNANCE

The third element of a vision for enhancing the ability of the public to negotiate and shape the health care environment in the 21st century is to enhance public involvement in health policy making and governance. As indicated by our earlier discussion of the current state of health policy decision making, this may require the development of a sustainable and independent infrastructure for the expression of voice by members of the public, by communities and neighborhoods, by "consumers," as well as by patients. The challenges here parallel the overall challenge of an information age democracy to enhance public participation in decision making. In the health care arena, there are also particular challenges.

Health is more salient to those who have an economic stake in the health sector than it is to the public as a whole, almost all the time. As we have noted above, there are exceptions, but these are likely to be for those who have a health problem. The perspective of those with health problems about the health sector are likely to be quite different from those of the population as a whole: They may be less interested in investments in prevention than they are in improving treatments; they may be less responsive to concerns about the health of populations in general than they are to concerns about how the medical care system deals with individual patients; especially if they are well insured, they may be far less concerned about the high cost of high-technology treatments. This is not to say that their concerns are invalid or irrelevant; it is to say that, if theirs is the only voice heard, we will not really be hearing from the public.

We live in a society with a pluralistic health care sector with multiple sets of decision makers and decision points. This also makes it more difficult for even a well-developed infrastructure to make strategically sound judgments about making one's case. This also creates a situation in which accountability can be misplaced. For example, it can be argued that at least part of the responsibility for the problems that have emerged in managed care can be given not just to the managed-care plans themselves, but also to the public regulators who have licensed the operation of these plans and to purchasers (private and public) who have made the decisions about what benefits they are expected to provide for which "covered lives" at what capitation rate. Most voice, so far, has been used to call attention to the failings of plans; little voice has been expressed toward the purchasers.

There are, nevertheless, opportunities. First, health has become, in the 1990s, a more political issue than it has been for several decades. This is true not only on a general level (witness the intensity of attention to the health care reform

debates), but also on a specific level, as in the intensity of concern for specific health issues, from breast cancer, to HIV/AIDS, to substance abuse, and to teen pregnancy. More recently, as already noted, managed-care "horror stories" have raised the political profile of more general health care concerns with a specific focus on "patients' rights." As the public begins to feel a loss of control in an area of their lives in which it seems important to have control, they seek alternatives. If they begin to recognize that they can no longer depend on their physician as the advocate (either because the physician has less influence over important decisions or because he or she has more clearly divided loyalties), they may be more open to the notion of seeking assistance from other kinds of advocates and counselors.

Nevertheless, we are left with the challenge of making health more salient to the public at large. In this regard, our best approach may be to elucidate and communicate not just the impact of society on health, but also the impact of health on society. In the international sphere, the profound connection between health and development (economic, social, political) has long been accepted in both directions. It is time to foster that understanding here in the US as well. The most engaged and sophisticated private sector purchasers of health benefits are those that recognize the importance of a healthy and functional workforce, with a similarly healthy and functional family as well, to productivity and performance. These purchasers do not care just about having inexpensive health benefits; they care about offering health plans that keep their workforce performing and minimize such indicators as days lost to work from illness or disability.

We need to increase the number of public and private policymakers, as well as members of the public, who make what for those in social medicine may be the "reverse" connection between health improvement and community and societal improvement. This will take a different kind of research, a different kind of partnering with those in other sectors, as well as a willingness to grant that health is not the only object of value to people in a vibrant democratic society. It may well be that only if health is seen as a powerful instrument, as well as an inherently worthwhile goal, will we be able to engage the public genuinely in taking on the systems that produce and sustain health.

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