

Cost-Effectiveness as a Criterion for Medical and Coverage Decisions

Understanding and Responding to Community Perspectives

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visible
fairness



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Front Cover: Six of the 263 discussion group participants.

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Cost-Effectiveness as a Criterion for Medical and Coverage Decisions

Understanding and Responding to Community Perspectives

Executive Summary

One of the greatest challenges facing health care today is increasing costs. This adversely affects every domain of health care, including the number of uninsured, accessibility, quality, continuity and consumer confidence in the health care system. Yet as a community of stakeholders, we rarely acknowledge publicly that resources are finite or work together on the challenges that this poses.

In January 2000, fourteen organizations joined with the nonprofit Sacramento Healthcare Decisions to plan and implement the Visible Fairness project. The goal of Visible Fairness was to better understand and respond to one specific dimension of the cost question: **the role of cost-effectiveness as a criterion in treatment and coverage decisions.**

While the topic of cost-effectiveness in health care is timely and substantive in its own right, Visible Fairness also focused on process elements that were important to achieving a more just and sustainable health care system. The project partners pursued Visible Fairness:

- *collaboratively* – working together as a coalition of health plans, medical groups, consumers, purchasers and others.
- *openly* – raising the often-avoided topic of cost containment as it relates to individual physician-patient treatment decisions.
- *inclusively* – targeting its inquiry on the views and values of both consumers and physicians.
- *realistically* – acknowledging that all stakeholders have a role in making constructive change, even when improvements are incremental.

Background

Visible Fairness emanated from Stanford University's Center for Health Policy effort to develop consistency in how the term *medically necessary care* is defined and applied across health plans and medical groups in California. Their 1999 project proposed a model definition that included cost-effectiveness as a criterion for determining if a treatment is medically necessary. Since cost-effectiveness has rarely been publicly acknowledged as a criterion for treatment or coverage decisions, the Visible Fairness project wanted to identify consumer and physician perspectives on whether, when, how and by whom it should be applied in making health care decisions.

Some cost-effectiveness decisions are straightforward, for instance when equivalent interventions have different price tags. Controversy surfaces most often when a health care intervention works slightly better but costs a great deal more than another intervention. Critical questions are:

- What constitutes a beneficial intervention and who decides?
- How much better must an intervention work to be considered necessary?
- How much is too high a cost relative to the benefit?

Project activities

Visible Fairness first sought the opinions and experiences of area physicians through individual interviews, a written survey completed by 512 area physicians and a physician discussion group. To identify consumer views and values, 263 area

residents participated in 25, two-hour interactive discussion groups. This process stimulated participants' discussion of competing priorities such as the desire to keep health care premiums affordable while having the most comprehensive health care available. The project also conducted a phone survey of 500 randomly selected individuals to provide a concurrent assessment of the public's views on health care costs.

Physician Perspectives: Summary of Key Findings

- **The role of cost containment and cost-effectiveness.** Physicians overwhelmingly accept the need to contain costs, believe that individual physicians should play a role in controlling costs and consider cost-effectiveness an appropriate criterion in individual treatment decisions.
- **Cost-effectiveness decisions at the bedside.** Although balancing cost with benefit seems to be an acceptable part of clinical decision-making in theory, there is no consensus on how to do so in practice. While some physicians believe it is their duty to offer patients all treatment options (including high-cost, low-benefit interventions), others believe this should be balanced with a duty to use health care resources optimally.
- **Patients' requests for care that is not cost-effective.** The frequency with which physicians report that patients insist on interventions that are not cost-effective appears to vary considerably, and physicians differ in how they respond when this happens. On average, half the time physicians report they do not order the intervention, even when the patient insists; nearly as often they *will* order it if the patient insists.
- **Discussing cost-effectiveness with patients.** The vast majority of physicians indicate that they will sometimes discuss cost or cost-effectiveness with their patients, while less than a quarter of

them report that they never do. Those that do discuss the issue report that patient response is almost evenly divided between anger and acceptance.

- **Practice guidelines.** There is a very high level of physician support for evidence-based clinical practice guidelines as a means to more cost-effective practice.

Consumer Perspectives: Summary of Key Findings

- **Cost-effectiveness as a criterion for physicians' treatment decisions.** Many, but not all, consumers will accept a physician's use of cost-effectiveness as one treatment criterion for individual patients. This is especially true when the patient trusts the physician, when it is clear that the patient is not forgoing a meaningful benefit, and when the physician's opinion is not coerced or financially rewarded.
- **Physicians discussing cost-effectiveness with their patients.** Though cost-effectiveness may play a role in physician decisions, consumers commonly say they do not want physicians to mention it. However, if the patient is paying out-of-pocket, discussions of cost are appropriate. If the health plans pays, discussions of cost sound like the physician cares more about saving the health plan money than about what is best for the patient.
- **Health plans using cost-effectiveness to deny treatment authorization for an individual patient.** Whereas cost-effectiveness may be acceptable when applied by trusted physicians, consumers are *not* likely to accept it as a reason for health plans to deny treatment authorization for an individual patient. Consumers believe that health plans cannot fairly judge cost-effectiveness because they care far more about the *cost* than the *effectiveness*. Even when health plans delegate

decision-making to physician organizations, it is a common perception that authorization decisions are made by “bean counters,” not by physicians.

- **Health plans providing guidelines for physicians to encourage cost-effective care.** While opposed to health plans making individual patient decisions, consumers are more willing to accept cost-effectiveness as one component of practice guidelines or coverage policies. Unbiased medical experts should develop these guidelines or policies, and individual physicians should be able to override them with appropriate justification. Consumer participation in health plan allocation decisions may increase member trust in health plan processes.
- **Health care as a shared or limited resource.** On a personal level, consumers view private health care coverage as an entitlement to an open-ended set of benefits, rather than a societal resource shared by many. Awareness of and concern about increased health care costs does not translate into a willingness to conserve health care resources that they feel are owed to them. Though they believe that costs should be better controlled, consumers do not support reductions in benefits or greater cost-sharing as a way to achieve this.

Recommended Strategies

Visible Fairness recommends that the major stakeholder groups – physicians, health plans, employers/purchasers, consumer organizations and others – prioritize and implement strategies that respond to the issues raised in this report. The strategies are intended to:

- Increase public awareness of the tension between what is medically possible and what is affordable.

- Expand the role of the health care consumer from patient to informed citizen.
- Encourage clinical guidelines and coverage policies that are responsive to consumer concerns, particularly if cost-effectiveness is a factor.
- Advance consumer participation in health system policies such as the allocation of patient care resources, design of new insurance products, patient grievance processes and coverage decisions.
- Promote mutually satisfactory and appropriate discussions between physicians and patients on cost-benefit trade-offs.
- Foster cooperative relationships among purchasers, consumers, providers and health plans towards addressing issues of health care equity, quality and cost.

The strategies listed below are described in greater detail in the body of this report.

I. Strategies for physician organizations

- Assess patients’ perceptions and experiences regarding physician-patient relationships and communication.
- Provide physician education programs on the ethical use of cost-effectiveness as a decision criterion.
- Sponsor training programs on improving communication between physicians and patients regarding joint decision-making and cost issues.
- Incorporate consumer concerns (identified on page 19) about the use of cost-effectiveness as a criterion for guidelines, clinical appropriateness and medical necessity decisions by individual physicians or medical groups.

II. Strategies for health plans, health insurance companies

- Identify information that plan members want and need regarding the plan's process for making coverage decisions.
- Provide easy access to information about the plan's decision-making processes.
- Bring plan members into decision-making at the appropriate organizational level regarding policies and processes that affect patient care and allocation of clinical resources.
- Assure that the plan's clinical guidelines (practice guidelines and technology assessments) and treatment approval decisions are responsive to the concerns raised in Visible Fairness (page 14).
- Assess physician use of evidence-based clinical guidelines and evaluate the extent to which this information has improved patient care.

III. Strategies for employers and purchasing cooperatives

- Provide in-service education programs or materials on basic information about health care insurance, delivery systems and costs of care.
- Include a process for employees or employee representatives to provide input in the selection of health plan benefits.
- Whenever possible, allow employees a choice of health plans and help them understand their differences.

IV. Strategies for consumer organizations and the media

- Develop and provide objective information for consumers, covering such topics as health care structure, financing and clinical decision-making. Distribute it through consumer assistance programs, disease-related groups and other consumer advocacy organizations.
- Encourage discussion and open debate on such topics as, "Have our expectations of medical science surpassed society's willingness to pay?"

- Address the importance of consumer responsibility as individual patients, as partners in decision-making and as citizens.

V. Strategies for academics, researchers, foundations and other non-aligned groups

- Pursue policy and clinical research on different models of incorporating cost-effectiveness criteria in health care decision-making.
- Develop and disseminate messages that increase consumer awareness about cost-benefit trade-offs and finite resources.
- Include consumers in developing and implementing policy-oriented projects on the equitable distribution of resources.

VI. Strategies for stakeholders working collaboratively

The public is better served when multiple groups work together to resolve common problems. It is especially critical that consumers and consumer organizations be involved in defining health care processes and practices related to allocation of patient care resources.

Collaborative issues related to system-wide cost-effectiveness include:

- Promoting a unified approach to quality measurement and reporting.
- Standardizing clinical treatment and patient education information.
- Jointly and visibly promoting evidence-based medicine as the standard for high quality clinical care.

Next Steps

Individual organizations are encouraged to evaluate their own needs, resources, interests and capabilities in determining which strategies can be undertaken. The strategies presented here are not all-inclusive and may stimulate ideas for other approaches.

Introduction

Background on Cost-Effectiveness

The rising cost of health care today is indisputable. While industry leaders may disagree on ways to address this, most agree that one major contributor to higher health care costs is the development of, and demand for, expensive medical technologies. With purchasers resisting increases in insurance premiums, plan members unhappy about greater restrictions and higher co-pays, and health plans under scrutiny for disputed denials of coverage, the question, “*What is worth paying for?*” may have more relevance now than ever before. This is particularly true in cases where certain medical interventions – diagnostic procedures, pharmaceuticals, and treatments – provide an incremental benefit at a very high cost. The balancing of cost with benefit is not new in health care, but it is not often discussed in the public arena.

The use of cost-effectiveness as a specific measurement in medicine has been limited to occasional *cost-effectiveness analyses* done by researchers who assess alternative clinical interventions in terms of their quantifiable costs and benefits. For many health care providers on the front line, cost-effectiveness is less science than it is intuition and experience – identifying the least expensive way to achieve a good result for a particular patient.

Project on Medical Necessity

In 1999, Stanford University’s Center for Health Policy completed a California-wide project titled, “Decreasing Variation in Medical Necessity Decision Making.”¹ The results of this project brought the issue of cost-effectiveness out in the open as it is applied in medical necessity decisions:

- Only two of the 34 health plan medical directors interviewed reported an evidence-based criterion for decision-making and only two included a cost-effectiveness criterion in their contractual definitions of medical necessity.
- In practice, when applying the concept of medical necessity to treatment authorization requests, medical directors ranked cost-effectiveness among the most common criteria used in deciding whether to authorize or deny an intervention.
- The final recommendations of the Stanford project proposed a model definition of medical necessity that incorporates a cost-effectiveness criterion for making determinations of medically necessary care for individual patients.²

The results of the Stanford project raised an important consideration: if health plans are using cost-effectiveness (however defined) in the process of clinical or coverage decision-making – or may be using it in the future as part of their medical necessity definitions – then more discussion is needed on the appropriateness and scope of its use. In particular, health care consumers need an opportunity to convey their own views and values on whether, when, how and by whom cost-effectiveness should be applied in making treatment or coverage decisions.

A Values-Based Concept

A common application of cost-effectiveness is the comparison of different medical interventions (such as clinical procedures or pharmaceuticals) for treating a particular medical condition. When one intervention works as well as another but costs twice as much, the health plan, medical group or

¹ Singer, S., Berghold, L. et al, “Decreasing Variation in Medical Necessity Decision Making”, California HealthCare Foundation, 1999. URLs: <http://chppcor.stanford.edu/lasso/pindex.lasso> (search “publications” by author and title) or <http://www.chcf.org/healthpolicy/view.cfm?itemID=1620>.

² See Appendix B of project report for model definition of medical necessity developed by a workshop of California stakeholders in March 1999. (Appendices included in Center for Health Policy website, see above).

physician may authorize only the less expensive one. Or, an intervention may qualify as cost-effective when it costs more initially but saves money in the long run by avoiding predictable future costs.

Controversy surfaces when an intervention works *slightly better but costs a great deal more* than another intervention. In this instance, choices may involve individual values that have no agreed-upon parameters:

- What constitutes a beneficial intervention and who decides?
- How *much better* must an intervention work to be considered meaningful?
- How much is *too high* a cost relative to the benefit?

These questions form the heart of the debate about the use of cost-effectiveness (balancing the cost of treatment with the benefit achieved) as a criterion in clinical or coverage decisions.

Project Leadership

Sacramento Healthcare Decisions (SHD) is a non-profit, community-based organization formed in 1994 whose purpose is to involve the public in health care policy and practice issues. SHD conceived the Visible Fairness project in 1999 to invite consumer perspectives into the discussion of cost-effectiveness as a component of determining medically necessary care. As a regional project, Visible Fairness included partners from many of the major health care interests – consumers, health plans, medical groups, physicians and purchasers – and together they formed the project Steering Committee (see inside front cover). A grant from the California HealthCare Foundation supported the project.

Methodology and Objectives

The hallmark of SHD projects is identifying the range of consumer values through the use of small interactive discussion groups. When there are no easy answers, individuals can be challenged to consider competing priorities by hearing, discussing and reflecting on the diverse views of their peers. The Steering Committee recognized the need to first understand the physician perspective on cost-effectiveness. Since the project's primary interest was the use of cost-effectiveness in bedside decisions (where physicians encounter the tension between cost and benefit when making treatment decisions), knowing physician views and experiences would influence how the subject was presented for consumer discussion.

The Steering Committee established several project objectives:

1. To determine how physicians perceive and implement cost-benefit trade-offs and how they communicate them to patients.
2. To identify principles, values and processes that consumers feel are most important for health care providers to consider when comparing different treatment costs and benefits.
3. To increase the visibility of cost-benefit dilemmas through the mass media and in professional and consumer publications.
4. To prepare recommendations, based on consumer and physician perspectives, for each of the major stakeholder groups on how cost-effectiveness could be addressed.
5. To demonstrate a model for integrating consumer and provider views based on constructive inter-organizational collaboration.

Project Activities

The project focused on identifying physician and consumer views and raising the visibility of this topic through a variety of communication strategies.

Physician Dialogue

- To provide guidance for the written survey, a dozen physicians were interviewed from a variety of health care settings, specialties and affiliations.
- A written survey was prepared and mailed to 1,000 practicing physicians in the five-county Greater Sacramento region.
- 512 valid, completed surveys were tabulated and analyzed.
- A discussion was held with eight physicians to learn their reactions to the survey results.

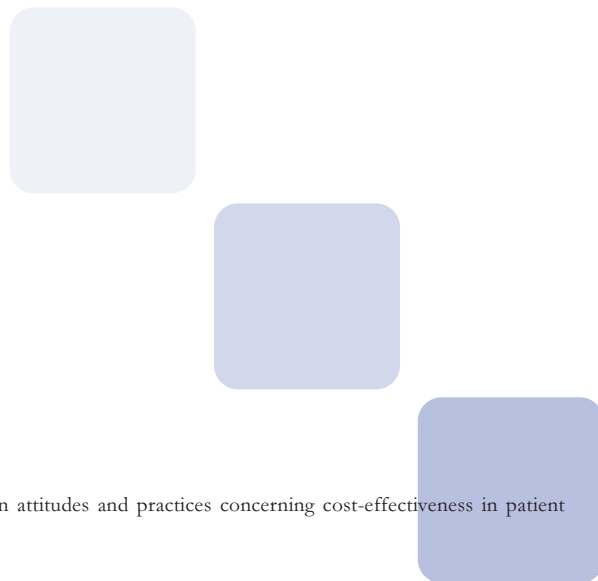
Consumer Dialogue

- A scenario-based discussion format was developed to identify consumer values regarding the use of high-cost medical interventions of marginal benefit.
- Twenty-five discussion groups were held – 21 of them in community settings and four as paid focus groups – involving a total of 263 community participants with a variety of demographic characteristics.
- Each two-hour discussion group was led by an experienced facilitator and tape-recorded, transcribed and analyzed.
- A phone survey was conducted of 500 local residents to capture quantitative data on consumer views and perceptions about health care costs.

External Communication

- *The Western Journal of Medicine* published an article on the results of the physician survey in its December 2000 issue³.
- *The Sacramento Bee* and *The Sacramento Business Journal* published multiple articles on the project.
- Participating health care organizations described the project and its activities in physician and employee publications.
- Project partners convened a community forum titled *Balancing Act: weighing the costs and benefits of medical treatment* in June 2001 to report the findings of the project activities. More than 250 health care professionals, organizational leaders and consumers from throughout the state attended it.

This report describes the key findings of the project activities and presents the strategies proposed by the Visible Fairness partner organizations. These recommendations are intended as a stimulus to promote systems and processes that are visible and fair regarding the use of cost-effectiveness in treatment and coverage decisions.



³ Ginsburg ME, Kravitz RL and Sandberg WA. A Survey of physician attitudes and practices concerning cost-effectiveness in patient care. *Western Journal of Medicine* 2000; 173:390-394.

Physician Perspectives

Many stakeholder groups play significant roles in health care delivery, yet the heart of medical care remains the relationship between physicians and patients. Visible Fairness conducted physician interviews and a written survey to contribute information to the consumer dialogue, to identify similarities and differences in how physicians and consumers perceive cost-related decisions, and to assure that the physician perspective was incorporated into the Visible Fairness recommendations.

Methodology

Visible Fairness conducted interviews with 12 area physicians from different specialties and affiliations to help formulate a 30-question written survey. The survey was mailed in June 2000 to 1,000 randomly selected practicing physicians in the five counties of Sacramento, Yolo, Placer, El Dorado and Nevada. The Sierra Sacramento Valley Medical Society provided the physician names and select demographics from its listing of all 3,200 identifiable physicians in the region. The mailing excluded physicians whose specialties were not in direct patient care (such as radiologists and pathologists). Project staff conducted a discussion group with eight physicians on the results of the survey.

Response

There were 512 respondents to the survey, representing a 52% return rate. The demographics of the respondents (age, gender and type of practice) were similar to those of non-respondents.

“There just isn't enough money in the system to do everything.”
Physician, individual interview

“Patients buy the Corolla and expect the Lexus.”

Physician, individual interview

However, respondents were slightly more likely than non-respondents (53% v. 42%) to be members of the region's four large physician groups, suggesting that solo or small group practice physicians were somewhat under-represented. Appendix B contains the complete survey instrument and responses.

Content

The survey questions covered physician opinions, perceptions and experiences in four areas of cost-effectiveness:

1. The role of cost containment and cost-effectiveness in medical decisions
2. Issues that make cost-effective practice difficult for physicians
3. Communication with patients about cost-effectiveness
4. Factors that help or hinder cost-effective medical practice

The survey described cost-effectiveness as:

A medical intervention (e.g., a diagnostic test, procedure, treatment, pharmaceutical, etc.) is cost-effective when, for example:

- *the intervention achieves a benefit comparable to an alternative intervention but at a lower cost; or*
- *the intervention achieves a greater benefit, even if at a higher cost than an alternative, and the added clinical benefit is worth the additional cost.*

Conclusions

1. Physicians accept the need for cost containment in general and believe that individual physicians should play a role in controlling costs.

- 92% agree strongly or somewhat that there is a legitimate need for cost containment in today's health care environment.
- 95% agree strongly or somewhat that as individual physicians they should play a role in controlling costs.
- 85% agree that the expense of a medical intervention should be considered, even when the patient is not paying all or most of the cost.

2. Physicians respond that cost-effectiveness is an appropriate consideration in patient treatment decisions.

- 88% agree (41% strongly and 47% somewhat) that cost-effectiveness is appropriate when weighing different medical interventions for their patients.
- Physicians are somewhat less in agreement that practice guidelines should include cost-effectiveness as a criterion (29% agree strongly and 54% agree somewhat).

3. Although physicians support the use of cost-effectiveness in principle, there is no consensus on how to apply it in practice.

- While 53% agree strongly or somewhat that the physician has a duty to offer any intervention with a chance of success and regardless of cost, 46% disagree strongly or somewhat with that statement.

4. Physicians indicate that the biggest barriers to practicing cost-effective medicine are related to societal pressures and patient expectations.

- Of nine factors listed as possible barriers to practicing cost-effective medicine, physicians ranked two of them significantly higher than the others: “society unwilling to acknowledge limits to health care resources” and “patients with unrealistic expectations of what medicine can do.”
- Physicians are least inclined to identify physician-related issues – such as being unaware of the costs of medical interventions – as significant barriers.

5. The frequency with which patients insist on care that is not cost-effective appears to vary considerably, and physicians differ in how they respond when this happens.

- While 54% of physicians report that they encounter this type of patient only occasionally, 33% say they do so several times a week and 9% encounter them several times a day.
- When this happens, on average, physicians say they do not order the requested intervention 56% of the time, even when the patient insists; 41% of the time they *will* order it if the patient insists.

“Patients acknowledge cost-effectiveness but don't accept this as a reason that they should not get a treatment.”

Physician, written comment on survey

6. Physicians vary in how often they discuss cost-effectiveness with their patients and report, on average, that patient response is divided evenly between anger and acceptance.

- Twenty percent of physicians never discuss cost or cost-effectiveness with their patients; 50% percent do so occasionally and 30% report that they do so frequently or always.
- Physicians report that about half the time patients become angry or upset when cost issues are raised; with similar frequency, patients accept cost-effectiveness when they understand that resources would be wasted.

7. There is a high level of physician support for evidence-based clinical practice guidelines as a means to more cost-effective practice.

- Eighty-five percent of the physicians indicate that these guidelines are one of three most useful ways to help practice cost-effective medicine. The next most frequently indicated methods were “talking with colleagues about best practices” (indicated by 54%) and “pharmacy advisories” (53%).
- The practices most indicated as a hindrance are “financial incentives tied to physician performance” (38%); “pre-authorization requirements for high-cost interventions” (37%); and “working in a capitated medical group” (28%).

“It’s much easier when we can say that the health plan won’t cover it. It reinforces our judgment without threatening our role as patient advocate.”

Physician, post-survey discussion group

Discussion

The survey provides valuable information on the environment in which physicians and patients experience the pressures of cost containment. These results – along with physician interviews before and after the survey and comments written by survey respondents – suggest conclusions as well as new questions about cost-effectiveness as part of clinical practice in the Greater Sacramento region.

- **Who Decides?** Since most physicians agree that cost-effective practices are important and necessary, the controversy may be less about *whether* cost-effectiveness should be a decision criterion and more about *who decides* what is cost-effective. It appears that physicians want the authority to *approve* treatments for their patients that they believe are cost-effective, but do not want the responsibility for *denying* treatments based on cost-effectiveness. This observation needs further exploration.
- **Duty to Patients.** While most physicians believe that they are the best judges of what is cost-worthy, there appear to be great differences in how physicians interpret their role as patient advocate in this cost-conscious environment. Some regard their duty to the individual patient as their only consideration while others believe this must be balanced with a duty to all their patients to spend communal resources optimally.
- **Response to Patient Demands.** While some physicians say they rarely acquiesce to patients who insist on unnecessary medical treatment, others do so frequently and without hesitation. It is unclear whether these variations are justified or signal an inequity in how patients are treated.
- **Discussing Cost.** Whether, when and how to talk to patients about cost-effectiveness varies considerably among physicians. Some seem to do

so with enthusiasm and success, while others completely avoid these discussions. If cost-benefit trade-offs remain a dominant issue in health care, physicians need to develop both their skills and comfort level with this topic.

- **Role of the Health Plan and Physician Organization Medical Director.** While many physicians resent the imposition of health plan or medical director rules and restrictions on their clinical decisions, physicians also find them to be a convenient foil when it is necessary and appropriate to say “no” to patients. This poses a dilemma: while blaming the health plan may avoid strain in the physician-patient relationship, is it constructive to undermine patients’ attitudes towards their health plans and managed health care in general?

- **Evidence-Based Guidelines.** Though there may be some reservations about cost-effectiveness being a criterion in clinical practice guidelines, there is considerable agreement among physicians about the benefit of evidence-based guidelines in helping practice in a cost-effective way. The logical follow-up questions: Are guidelines available? Are they being used? Are they effective? Who should develop them?
- **Limited Resources.** Physicians believe that many external factors make it difficult to practice cost-effectively and that the biggest obstacle is that society has not come to terms with the fact that health care resources are limited. Given this perception, it is not surprising that physicians are ambivalent at best about making and discussing individual patient decisions based on cost-effectiveness.

“It breaks the relationship with the patient if you are prescribing based on cost. Let someone else say it’s not affordable.”

Physician, post-survey discussion group

Consumer Perspectives

To identify consumer perspectives, Visible Fairness convened small group discussions with Greater Sacramento area residents in a variety of settings. This interactive process allowed participants to discuss their reactions to cost-effectiveness scenarios and to respond to the views of their peers. Though the format for the discussion was highly structured, this open-ended, non-directive approach fostered understanding of the multiple issues at stake and helped to identify individual values and principles.

Purpose of the discussion groups

Visible Fairness sought to understand:

- How consumers respond to cost-effectiveness as a medical treatment criterion.
- What should be considered if/when cost-effectiveness is a criterion for treatment decisions or coverage policies.
- Whether and how cost issues should be communicated to patients or plan members.
- How consumers respond to the tension between maximizing health care services for the individual and controlling costs for society.

The term “cost-effective”

Cost-effectiveness was illustrated in several ways:

- If an expensive medical intervention works only slightly better than an inexpensive intervention, should the expensive one be prescribed by the doctor and covered by the health plan?
- If an expensive medical intervention provides little or no medical benefit, should it be paid for by the health plan?

- If health plan dollars can achieve better health outcomes for their plan members by providing a particular medical intervention, should it pay for that intervention *instead of* paying for other interventions that are less cost-effective?

“When they don’t let you, then there is always a thought in the back of your mind, ‘they should have given me that, I could have been better.’”

Community member

Participants

Community members voluntarily organized 21 discussion groups in local settings such as churches, workplaces, classrooms and private homes. Specific groups were recruited to optimize diversity of the participants by age, ethnicity and insurance status. Since these were volunteer groups, demographic characteristics such as income and education level were not asked. Four additional sessions were held as paid groups to target individuals with specific demographic characteristics that had been under-represented in the community groups. Appendix C shows a listing of all of the discussion group settings and the demographics of the participants. Health care professionals were not included in the discussion groups.

Scenario-based discussions

Beginning with a 10-minute overview of the topic, an experienced facilitator led a two-hour discussion with 8-12 participants in each of the 25 groups. The sessions used three different scenarios as discussion starters. These scenarios (see Appendix C) exposed participants to examples of cost-effectiveness being applied in practice or policy and provided a context in which public values and priorities could be expressed and explored. The goal was to identify the range of consumer views and values and to elicit ideas for resolving conflicts and seeking constructive solutions, rather than to educate consumers or to seek consensus. All discussion groups were tape-recorded, transcribed and analyzed. The results were consolidated, identifying themes, concerns and values.

Conclusions

ISSUE 1. Cost-effectiveness as a criterion for physicians' treatment decisions

Many, but not all, consumers accept cost-effectiveness as a reasonable criterion when doctors consider treatment alternatives for individual patients.

Although they believe that physicians should not think at all about the cost (when health insurance is paying), consumers recognize that cost pressures are everywhere in health care now. In general, consumers believe that a very small incremental benefit may not justify a very high price tag, regardless of who is paying. To base a patient care decision on this type of cost-benefit trade-off, however, requires consideration of several factors:

- Cost-effectiveness should not be the *only* criterion or the *main* criterion by which physicians make decisions.

- Individual characteristics of the patient and the patient's situation are essential factors. For example, life-saving interventions should be viewed much differently than minor medical remedies. If there are other steps patients could take before trying an expensive intervention, then that is where they should start. The long-term cost implications should also be taken into account, not just the short-term costs.
- The patient's belief that a treatment will help should be considered, if denying that treatment would add to the patient's stress. Even when medical need is not evident, doctors should be flexible enough to take individual patient needs into account.

Others do not accept any cost-related criteria. Unless patients have to pay for the treatment themselves, these consumers believe that financial considerations have no place in physicians' decision-making.

While opposed to wasting money, these consumers believe that any treatment that offers a benefit to the patient – no matter how small the benefit – is one to which the patient is entitled. The decision to accept that treatment belongs to the patient, not the doctor or the health plan.

“But you are trying to tell me that my life is not important because of the dollar amount. You are putting a price tag on my life and I don't appreciate that.”

Community member

ISSUE 2. Physicians discussing cost-effectiveness with their patients

When people have health insurance, most feel it is not appropriate for doctors to mention cost-effectiveness when discussing treatment options.

Though “cost” is not the same thing as “cost-effective,” most consumers have a strong visceral reaction to physicians using the word cost in any patient care context. Even those consumers who accept cost-control as a necessary (or even essential) aspect of health care today are uncomfortable with the idea of their physician referring to it explicitly when discussing treatment options. They would rather have their physician talk only about how certain treatments would help them or not.

Those who do not object to the cost discussion feel that it is better to know all the factors that doctors take into consideration.

For these consumers, trust in their doctor means a frank and honest discussion about what influences decision-making. They are not offended by cost discussions. But timing is everything. Patients should not be made to feel that cost is a factor in life and death situations.

ISSUE 3. Health plans providing guidelines for physicians to encourage cost-effective care

For most people, it is acceptable for health plans to have guidelines for when treatments are covered, as long as these are based on unbiased expertise and are “guidelines” rather than absolute rules.

For consumers, there is little distinction between health plans promoting clinical practice guidelines (that provide models of best practice) and defining their coverage processes (that spell out the circumstances in which a medical treatment will be paid by the health plan). Both are regarded as an intrusion in the physician-patient relationship: *“Bean counters shouldn’t be telling doctors how to practice medicine.”*

Nevertheless, consumers see some advantages to the use of guidelines, such as reducing wasteful spending, promoting high quality medical care, and protecting physicians from malpractice claims. But consumers believe that practice guidelines or coverage decisions must be flexible, allowing for inevitable variation in patient circumstances.

Creating the guidelines

Consumers have a variety of suggestions for how guidelines are created or authorization decisions are made:

- Base them on scientific evidence, not just on treatment expense.
- Involve physicians with special expertise.
- Develop guidelines using an independent body that does not have financial ties to the health plan.
- Involve consumers or health plan members in various decision processes, such as grievances about treatment authorizations and decisions on how health plan dollars are allocated for clinical services.
- Demonstrate that dollars saved through cost-containment efforts are being used for patient care, rather than for administrative salaries or stock dividends.

“It would depend on the situation. Everyone is different and you can’t make rules that are going to apply across the board.”

Community member

Physician use of guidelines

Consumers are more accepting of health plan guidelines for clinical practice if:

- Doctors can override them by showing a valid reason for an exception.
- Exceptions are decided through a timely review process.
- Only physicians with special expertise can overrule the patient's physician.

Though consumers believe that the doctor is in a better position than the health plan to know what the individual patient needs, as one community member noted, *"This is life – we all have to live by guidelines."*

ISSUE 4. The individual vs. the common good

Most consumers have a difficult time “wearing both hats” – that of consumers/patients seeking to get the best medical care possible (and maximizing their health benefits) and that of citizens/taxpayers concerned about the rising cost of health care for everyone.

- Some feel it is not the responsibility of consumers to help control health care costs. This view is based on one or more beliefs:
 - The burden of reducing health care costs should be borne by the other players – e.g., high drug prices should be restricted, waste and abuse should be reduced, health plan profits should be controlled, etc.
 - Their health coverage is a contract with the health plan for the “best” health care. They pay their premiums and will not settle for anything less.

- They are not concerned that costs continue to rise. To get the best care, it is appropriate that costs will increase. It is the responsibility of individuals, employers and the public sector to pay whatever is needed.

“I think that talking about your own personal care, I’m not sure that you really want to hear about how it is going to save the health care system. You want to make sure it is something that is right for you.”

Community member

- Others understand the concept of “shared resources” and are aware of the connection between the type/cost of medical care for individual patients and the cost of health care for everyone. While genuinely concerned about rising costs, they cannot or do not want to let this influence the medical treatment they expect for themselves or their loved ones.
- A few embrace the concept of shared resources completely. They say they make every effort to use health care appropriately and sparingly. Said one community member, *“When the health plan pays for something, we all pay.”*
- Many younger and healthier consumers – having little experience with illness – voice no opinion on this because they have never thought about it before or have never faced it as an issue with their doctors or health plans.

Related Themes

For consumers, cost-effectiveness as a decision criterion does not exist in isolation from other health care perceptions, relationships, processes and policies. The following themes emerged that were closely entwined with discussions of balancing cost with benefit.

Trusting the physician

In all decisions involving patients, physicians and health plans, the trust that patients have in their own physicians is the most critical prerequisite to accepting any type of limit-setting decision.

Consumers believe that doctors are being continually pressured by the health plans to hold down costs; nevertheless, consumers expect their doctors to fight on their behalf if the health plan is denying needed care. If a physician they trust does not believe a treatment will offer a meaningful benefit, consumers can accept that – as long as this is the physician’s professional judgment and is not influenced by the physician’s own financial incentives.

Partners in decision-making

Consumers believe that the patient and doctor should be partners in decision-making about treatment choices. Mutually agreed decisions are the best, but many believe that the patient should have the last word.

It was widely expected that doctors will tell patients about all the treatment options – even those not covered by the health plan. To be informed health care users, consumers feel they must know all their options. Closely linked to this is the value consumers place in choice; they want to have options, however restricted. Thus, if a patient and doctor disagree on what is a necessary treatment, patients want to know that there may be alternative actions, such as to:

- Re-evaluate the situation in a couple months.
- Negotiate a compromise (e.g, share in the cost of the treatment or institute a trial period).
- Get a second opinion from another doctor.
- Pay for the treatment themselves. Having the option to pay out-of-pocket was mentioned repeatedly, and many were annoyed that their doctors did not discuss this option with them.

Consumer responsibility

There is a strong and vocal belief that consumers need to take more responsibility in their role as health care recipients, to improve their individual well-being as well as to reduce costs.

Consumers say this responsibility should be manifested in several ways, such as to:

- Maintain a healthy lifestyle and follow self-care measures that will improve their health status (e.g, diet and exercise instead of relying on medications alone).
- Learn more about their medical condition and treatment options through outside sources and not relying on the doctor (or neighbor or drug advertising) as the only source of information.

“Too many people do not feel responsible, they just want to pop a pill. They won’t do the work that is involved in being healthy.”

Community member

- Learn how their health plan works and the specifics of their coverage (though many are skeptical that consumers will do this unless they have a conflict with their plan).

The role of the health plan

Many believe that health plans exist solely to maximize profit and pressure doctors to spend as little as possible, at the expense of high quality medical care.

The doctor-patient relationship is considered sacrosanct, and the intrusion of a third party (which seems to care only about the bottom line and not about patients) is difficult for most to accept. A common view is that the health plan should exist only to pay the bills and not to tell doctors how to practice medicine.

“I think that one of our major criticisms of HMOs is all we see is a bureaucracy telling this little patient no.”

Community member

Additional Observations

- **Many consumers lack fundamental knowledge of health costs and health insurance.** Most people understand explicit health plan exclusions, but they do not understand how something could be a covered treatment and not available to them. Though they know that the doctor must approve a treatment for it to be paid by the health plan, for many it seems arbitrary that patients cannot get a treatment when they believe they qualify. Consistent with the view that the patient should be the primary decision-maker,

many believe that the patient, not the physician, is the best judge of what is medically necessary (though they do not use that term). Regardless, they still believe that the physician is their one ally in this complicated system.

Even among well-educated participants, there is a dearth of knowledge about health care systems, costs and financing. Though the discussion groups were not designed to assess participant knowledge, the discussions revealed that there was little understanding of such things as why health care costs continue to increase, what the actual costs of treatments and services are, the employer’s role in determining scope of coverage, and the financial relationships among health care entities including capitation and delegated decision-making.

- **Comprehensive coverage may be a greater priority than reducing health care expenditures.** The results of the telephone survey of 500 consumers (Appendix D) suggest that relatively few respondents support options that set limits on health care coverage. Despite concern about increasing health care costs, more than two-thirds of respondents agree that health plans should cover all advances in medicine even if this results in higher insurance rates. Additionally, increased patient responsibility for health costs is not a popular option, with just 35% agreeing strongly or somewhat that patients should pay a greater part of the health care bill so they will be more cost-conscious. Most believe that health plans are the major driver of cost inflation because “they care more about profits than about patient care.”

Appendix D includes greater discussion of the survey results, and Appendix A is a summary comparison of consumer and physician perspectives.

Recommended Strategies

These strategies address consumer and physician concerns about limit-setting in an environment of finite health care resources. Some relate specifically to cost-effectiveness as a decision criterion; others speak to the more general but related issues of communication, trust, consumer participation and the need to foster a more informed citizenry regarding health care costs, systems and policy. These strategies are intended to:

- Increase public awareness of the tension between what is medically possible and what is affordable.
- Expand the role of the health care consumer from patient to informed citizen.
- Encourage clinical guidelines and coverage policies that are responsive to consumer concerns, particularly if cost-effectiveness is a factor.
- Advance consumer participation in health system policies such as the allocation of patient care resources, design of new insurance products, patient grievance processes and coverage decisions.
- Promote mutually satisfactory and appropriate discussions between physicians and patients on cost-benefit trade-offs.
- Foster cooperative relationships among purchasers, consumers, providers and health plans towards addressing issues of health care equity, quality and cost.

Implementing the Strategies

The nature of health care systems necessitates an integrated approach to addressing cost-effectiveness and related issues. Although these strategies are presented as they apply to different stakeholder groups, success will likely depend on the

cooperation and commitment of a variety of health care interests.

Many of the strategies address the lack of consumer information and knowledge about delivery and cost of health care and the tension between what is desirable and what is affordable. However, education alone is not likely to have a meaningful impact. If consumers are to believe that health care systems are fair and reasonable – even when faced with limited resources – they need to feel confident that there are trustworthy processes in place.

In prioritizing these strategies, each organization needs to decide which one(s) are most congruent with its current needs, resources, interests and capabilities. These strategies do not exhaust the possibilities for constructive change but reflect the themes and issues revealed in the Visible Fairness project.

I. Strategies for physician organizations

Physicians have a central role in addressing cost-benefit trade-offs: they recognize their own responsibility to deliver cost-effective medical care; consumers rely on them to appropriately weigh the costs and benefits for individual patients; and health plans depend on them to use health care resources wisely. Recommended strategies:

- A. Assess patient perceptions.** Medical groups and Independent Practice Associations (IPAs) can actively seek the perspectives of their patients – e.g., through surveys or focus groups – on the current state of patient-physician relationships, especially communication about treatment options. While current surveys tend to focus on service aspects of health care, more is needed on the dynamics of patients as health care partners.

B. Explore the role of cost-effectiveness in medical practice. Physician groups and associations can provide physician education programs on such topics as:

- The ethics of using cost-effectiveness as a treatment criterion.
- How cost-effectiveness criteria are different from *appropriateness* or *evidence-based criteria*.
- The practice of “blaming the health plan” for denial of treatments that the physician would not have approved anyway.

C. Improve communication between physicians and patients. Physician groups can provide education programs on such topics as:

- Understanding the patient perspective: why the word “cost” is so threatening.
- How to talk with patients who believe that “you’re just trying to save money.”
- When and how to discuss cost-benefit trade-offs with patients.
- The art of making joint patient-physician decisions and mutually agreeable compromises.

D. Incorporate consumer concerns. If cost-effectiveness is a criterion used by physicians or physician groups, consumer concerns need to be addressed when treatment decisions are being considered:

- Is the treatment critical to the patient’s health status and quality of life?
- What is the risk of forgoing the more costly but more effective treatment?

- Do the patient’s particular situation and individual characteristics require a different approach?
- Is the physician’s or medical group’s decision influenced by financial incentives?
- Will a compromise solution be explored if the patient truly feels that the treatment would help though the physician does not?
- Will all treatment options be described to the patient, even those not covered by the health plan?
- Does the patient have the option of paying for a treatment out-of-pocket if it is not covered by the health plan?

II. Strategies for health plans and health insurance companies

A. Identify information that members want.

Conduct focus groups or surveys of plan members to learn what they feel is important to know about how their health plan makes coverage decisions.

B. Provide easy access to information about the plan’s decision-making processes.

Through existing member communications – e.g., orientation materials, newsletters, website – establish and promote access to the health plan’s clinical guidelines, coverage policies and grievance processes. Additional topics can be covered such as:

- The role of the health plan (and delegated medical groups, if indicated) in the health care delivery process.
- The process by which health plan coverage policies are developed.

- The role of the health plan in approving/denying treatment requests.
- The difference between medically necessary care and a covered benefit.
- The difference between practice guidelines and coverage policies and how to read and interpret these policies from a member point of view.
- If cost-effectiveness is used as a criterion to reduce inefficient spending, give members information on who makes these decisions and the process used in determining cost-effectiveness.

C. Bring plan members into decision-making.

Create and evaluate processes and structures that bring health plan members into organizational decisions directly affecting its members. Such decision-making areas could include:

- Allocating patient care resources, such as formulary decisions and coverage of new technology.
- Developing new models of health plan coverage and cost-sharing.
- Participating in member-plan dispute resolution processes.

D. Make clinical guidelines compatible with consumer priorities.

Assess current and future guidelines for their congruity with the priorities identified by consumers:

- Clinicians with recognized expertise develop guidelines that are evidence-based.
- Those without financial ties to the health plan or medical group develop or approve the guidelines. If this is not feasible, health plans

should describe how the process is accomplished.

- Allow physicians to seek exceptions to the guidelines without undue delays or obstacles.
- Tell health plan members that guidelines exist; how they are developed, updated and applied; and how members can receive them.
- Inform plan members how and by whom guideline exceptions are approved.

E. Assess physician use of clinical guidelines.

Determine the extent to which physicians are using clinical guidelines; employ current research on promoting effective adoption and implementation; and evaluate the extent to which these guidelines have improved patient care. Where appropriate, expand the use of evidence-based guidelines.

III. Strategies for employers and purchasing cooperatives

A. Provide in-service education programs.

Promote attendance as part of new employee (or new plan member) training. Include information on such topics as:

- Why healthy people need to know how the health care system works.
- The roles and relationships of employers/purchasers, health plans, physicians, patients, health care facilities, pharmaceutical companies, etc.
- How employers decide on health plan benefits.
- Why health care costs increase and the consequences.

- Understanding health plan coverage policies.
- Basic definitions and questions to ask when choosing a health plan or physician.

B. Give employees a voice. Incorporate mechanisms for employees or employee representatives to provide input on the selection of health plan benefits.

C. Provide choices. Whenever possible, allow employees choice of health plans and help them understand the differences between them.

IV. Strategies for consumer organizations and the media

A. Provide objective information. Organizations such as consumer assistance programs, the Office of the Patient Advocate, the Department of Managed Health Care, disease-related groups and other community-based organizations can increase consumer knowledge by developing and/or distributing materials that address health care policy, structure and financing. Such topics might include:

- How the various health care players (purchasers, health plans, hospitals, physicians, etc.) inter-relate in the provision of medical services.
- Why health care costs increase and what individuals can do to hold down costs for themselves and others.
- What doctors and health plans look for when deciding if something is “medically necessary.”

B. Encourage open debate. Influential organizations such as AARP, the League of Women Voters, Consumers Union, Health Access and others should provide written

information, promote discussion and encourage open debate on the question, “Have our expectations of medical science surpassed society’s willingness to pay?”

C. Address consumer responsibility. Consumers must advocate for their own needs while understanding their role as partners in health care. Consumers need to:

- Adopt healthy habits. Much of what keeps people healthy is self-care measures.
- Recognize there is a great deal that is unknown in medicine. If patients have a chronic condition, they should learn as much as they can about it. This will prepare them for discussing their own role in health maintenance and making decisions with their physician about the best course of treatment.
- Learn more about health care systems and the policies that affect health care delivery. Consumers need to see themselves not only as patients but also as citizens who can have an informed voice in how health care is delivered.

V. Strategies for researchers, philanthropic foundations and other non-aligned groups

Independent organizations and research groups can study and communicate health care issues related to cost-effectiveness. For example:

- Pursue policy and clinical research on models of incorporating cost-effectiveness criteria in health care decision-making.
- Develop and disseminate messages that increase consumer awareness about cost-benefit trade-offs and finite resources.

- Include consumers in developing and implementing projects on the equitable distribution of resources.
- Investigate the tension between the quest for new medical treatments and the willingness/ability to pay.
- Produce journal articles, op-ed pieces, and conference presentations on cost-effectiveness to a variety of stakeholder groups, including elected officials who represent all positions in the health insurance debate.
- Develop relevant health policy curricula for secondary school and college courses.
- Apply cost-effectiveness analyses to relevant clinical areas.

interests. Efforts related to system-wide cost-effectiveness in health care practice include:

- Identifying and promoting methods for reducing inappropriate variation in clinical practice.
- Developing consistent messages for consumers on important public health issues (e.g., the overuse of antibiotics).
- Promoting a unified approach to quality measurement and reporting.
- Standardizing electronic communication among stakeholders to reduce administrative inefficiency.
- Standardizing clinical treatments and patient education information.
- Jointly and visibly promoting evidence-based medicine as the standard for high quality clinical care.
- Collaborating on new models of health care coverage that take into account the issues raised in Visible Fairness.

VI. Strategies for stakeholders working collaboratively

Regardless of competition, there are numerous aspects of health care delivery that are priorities for all stakeholders. The public is better served where different groups can develop and pursue common

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Appendix A

Comparison of Consumer & Physician Perspectives

These are the major themes in the Visible Fairness discussions and surveys of consumers and physicians. The diversity of viewpoints among the respondents was extensive. The following summarizes the prevailing views of these two groups and not the totality of perspectives that were expressed.

	Consumer Perspective	Physician Perspective
The role of cost-effectiveness in medical decisions	Balancing cost with benefit is acceptable as long as other factors are dominant considerations.	Cost-effectiveness--and other cost containment strategies--are necessary but difficult aspects of practicing medicine today.
The role of guidelines in treatment decisions	Guidelines (that take cost-benefit trade-offs into account) are acceptable as long as expert doctors write them and the patient's doctor can override them when appropriate.	Current guidelines can be very helpful but more evidence-based guidelines are needed. Physicians do not know if cost-effectiveness is now included as a criterion.
The role of third parties in issuing denials	Health plans should not override patient's doctor nor should they pressure doctors to say "no."	Medical group or health plan denials are often useful so treating physicians do not have to say "no" to patients. This helps maintain the physician's role as patient advocate.
Communicating with patients about cost-effectiveness	Doctors should not discuss cost-related issues unless the patient must pay for the treatment him/herself.	It is best to avoid discussing cost-effectiveness with patients unless the relationship with the patient is a strong one.
Patients' view of health insurance	Though patients should do more to keep themselves healthy, individual patients are entitled to maximize their health plan benefits.	Patients assume that their health insurance entitles them to "everything" and, unless they are self-pay, there is little to motivate patients to judicious use of health care dollars.
The concept of shared or limited resources	While most accept that there are limited resources, as patients they expect to receive the "best" medical care. If limits are set, it is better for doctors to do this on a case-by-case basis rather than the health plan making blanket exclusions.	Though aware of the impact that all treatment decisions have on total costs, most are uncomfortable or unwilling to take societal needs into account when treating individual patients. Limits should be set but not by physicians at the bedside.



SURVEY RESULTS
 Survey was mailed 6/5/00
 and tabulated 7/15/00

Cost-Effectiveness in Medical Practice

A Survey to 989 Sacramento Area Physicians
 (512 responders)

Visible Fairness Project
 c/o Sacramento Healthcare Decisions
 4747 Engle Road
 Carmichael, CA 95608

Cost-effectiveness: For the purpose of this survey, a medical intervention (e.g., a diagnostic test, procedure, treatment, pharmaceutical, etc.) is cost-effective when, for example:

- *the intervention achieves a benefit comparable to an alternative intervention but at a lower cost; or*
- *the intervention achieves a greater benefit, even if at a higher cost than an alternative, and the added clinical benefit is worth the additional cost.*

1. Do you agree or disagree with the following?

	Agree strongly	Agree somewhat	Disagree somewhat	Disagree strongly
(a) There is a legitimate need for cost containment in today's healthcare environment.....	56%	36%	5%	2%
(b) As individual clinicians, physicians should play a role in helping to control healthcare costs.....	61	34	4	1
(c) It is inappropriate for anyone other than the treating physician and patient to decide if a treatment is "worth the cost".....	42	30	23	5
(d) If a medical intervention has any chance (no matter how small) of helping the patient, it is the physician's duty to offer it regardless of cost.....	23	30	29	17
(e) The only time the cost of a medical intervention should be considered is when the patient must pay all or most of the cost.....	5	9	30	55
(f) It is appropriate that clinical practice guidelines include cost-effectiveness as a criterion.....	29	54	10	7
(g) It is appropriate that physicians consider cost-effectiveness when weighing different medical interventions for their patients.....	41	47	9	3

2. How much, if at all, do you feel the following issues make it difficult for physicians to practice cost-effective medicine?

	Contributes to difficulty?			
	A great deal	Somewhat	A little	Not at all
(a) Inadequate information on the cost-effectiveness of medical interventions.....	40%	46%	12%	1%
(b) Patients with unrealistic expectations of what medicine can do.....	62	31	6	1
(c) Coverage decisions that consider only the short-term benefits for patients, but not the long-term benefits	41	45	11	3
(d) Patients not directly sharing the cost of their medical interventions....	43	42	12	3
(e) Society unwilling to acknowledge limits to healthcare resources.....	66	27	6	1
(f) Physicians being unaware of the costs of medical interventions.....	24	50	22	5
(g) The need to practice defensive medicine.....	39	46	14	1
(h) Direct-to-consumer advertising about drugs and treatments.....	44	38	15	3
(i) Physicians unwilling to refuse patients' demands for unnecessary interventions.....	21	53	22	4

3. How often do you encounter patients who insist on having a medical intervention that you regard as not indicated or not cost-effective?

Several times daily **9%** Several times a week **33%** Occasionally **54%** Never **4%** (if "Never", go to question 7)

N = 471

4. If a patient insists on a medical intervention (e.g., a medication or diagnostic test) that you believe is not indicated or not cost-effective, in general what percentage of the time do you do each of the following?

- (a) I try to explain why the intervention is not appropriate and do *not order it*, even if the patient insists..... **56%**
- (b) I try to explain why the intervention is not appropriate but *order it anyway*, if the patient continues to insist... **34%**
- (c) I do not try to talk the patient out of the intervention and will order it unless it will do the patient harm..... **7%**
- (d) Other (please explain): _____ **3%**

N = 483

5. When a patient asks for a medical intervention that you do not consider indicated or cost-effective, how often do you refer to the cost or cost-effectiveness of the intervention as part of your discussion with the patient? (exclude those instances where the patient pays all or most of the cost)

Always **6%** Frequently **24%** Occasionally **49%** Never **21%** (if "Never", go to question 7)

N = 364

6. When you do mention cost or cost-effectiveness with patients who do not pay the cost themselves, what percentage of the time do patients respond as follows?

- (a) Patients get angry or upset if cost or cost-effectiveness is mentioned..... **45%**
- (b) Patients accept this once they understand that the intervention would waste resources..... **49%**
- (c) Other (please explain) _____ **6%**

7. How useful are the following in helping you to practice in a cost-effective way?

- **Please check up to three (3) things that are the most useful.**
- **Also check any that you feel hinder you from practicing in a cost-effective way.**

	Check 3 that are (or would be) most useful:	Check any that hinder:
(a) Evidence-based clinical practice guidelines and/or pathways.....	85%	2%
(b) Physician profiles on frequency of ordering tests, procedures, drugs, etc..	20	20
(c) Pre-authorization requirements for high-cost interventions.....	14	37
(d) Working in a capitated medical group.....	9	28
(e) The use of formularies.....	30	17
(f) Financial incentives tied to physician performance.....	4	38
(g) Pharmacy advisories (information on efficacy and cost).....	53	4
(h) Talking with colleagues about best practices.....	54	2
(i) Education on how to respond to patients' requests.....	22	3

8. Would you be willing to participate with a group of physicians to discuss the composite results of this survey?

Yes **27%** No **68%** Maybe **2%** No Response **3%**

If "Yes", please write your daytime phone number and/or email address: _____

If you have any additional comments you'd like to make, please note them here:

Appendix C

Discussion Groups: Settings and Participant Demographics

25 Discussion Groups (held Nov 2000 - Feb 2001)

Workplace Settings

Lutheran Social Services staff
 Placer County Senior Peer Volunteers
 Area 4 Agency on Aging staff
 Sac. County Dept. of Human Assistance staff
 Sac. County Dept. of Human Assistance Advisory Comm.

Educational Settings

Clinical Pastoral Education students at UCDCM
 Masters in Social Work students at CSUS (2 classes)

Church Settings

Lutheran Church of the Cross
 St. Andrews AME Church
 Grace Lutheran Church

Civic Organizations/Support Groups

100 Black Men
 Lions Club of Galt
 Grey Panthers / Older Women's League Members
 League of Women Voters' Health Committee
 Fibromyalgia Support Group
 Family Caregivers Support Group

Demographic-specific

Medi-Cal recipients
 Those without health insurance
 Middle-class Hispanic group
 Those with a health plan dispute

"Friends & Neighbors"

4 groups

Total Number of Participants: 263

Gender		Age		Disability / Chronic Health Condition	
Male	32%	18-30	11%	Yes	36%
Female	68%	31-50	38%	No	64%
		51-64	28%		
		65-80	19%		
		81+	3%		
		No response	<1%		

Health Insurance		Ethnicity		County of Residence	
None	7%	African-American	16%	El Dorado	<1%
Medicare	20%	Asian	4%	Placer	10%
MediCal	5%	Caucasian	66%	Sacramento	81%
Employer Pays All	28%	Hispanic/Latino	9%	Yolo	2%
Employer Pays Some	27%	Native American	<1%	Other	7%
Individual Pays All	12%	Other	2%		
No response	1%	No response	3%		

Appendix C

Discussion Groups: Scenarios

Each of the consumer groups used two of the following three scenarios as tools for discussions. *Fred Jones* was used in all 25 groups, *Happy Valley Health Plan* was used with 17 groups and *Stay Well Health Plan* was used in eight groups.

These discussions exposed participants to examples of cost-effectiveness being applied in practice or policy, providing a context in which public values and priorities could be expressed and explored. The individual “voting” at the beginning of a scenario discussion was done to elicit each person’s perspective and provide a basis for initiating group discussion.

#1 Fred Jones

Fred Jones is 63 years old and has a history of high blood pressure and high cholesterol. Two years ago he had a mild stroke from which he completely recovered. His physician Dr. Smith has Fred on a specific diet, an exercise program and a low-dose aspirin every day to reduce his risk of another and perhaps more serious stroke. Aspirin has been proven to be an effective way to reduce the risk of stroke.

One day Fred is talking with his neighbor who tells him that she heard about a medication called “Strokamine” which works better than aspirin in preventing stroke.

At his next appointment with Dr. Smith, Fred asks about Strokamine. Dr. Smith explains that while medical studies show that it works 10% better than aspirin (with no additional side effects), it also costs \$1,500 per year rather than the \$5 per year that aspirin costs. Dr. Smith says he doesn’t believe that the very small benefit of using Strokamine is worth its high cost.

Though he hasn’t had another stroke so far, Fred is concerned that he is not getting the most effective treatment available, especially since he has health insurance that would have paid for Strokamine if Dr. Smith had ordered it.

Do you think Dr. Smith should have ordered Strokamine for Fred instead of aspirin?

Yes ___ No ___ Not sure ___

#2 Happy Valley Health Plan

Happy Valley Health Plan has contracts with several large companies to provide health insurance for their employees. These companies have recently informed Happy Valley that they cannot pay higher premiums this year for their employees’ health insurance. Since the cost of medical care continues to increase each year, Happy Valley has to figure out how to provide all the medical care that its members need when the insurance premiums aren’t going to keep up with the cost of care. So Happy Valley decides it will try to avoid paying the cost of medical tests that have little or no proven benefit for patients.

Happy Valley establishes guidelines for the use of MRIs – one of the most expensive tests that doctors can order. Happy Valley knows that many of these MRIs are ordered for patients even when scientific studies have shown that the MRI is extremely unlikely to help in diagnosing certain problems. One of the most common examples of this is when an MRI is ordered for patients with uncomplicated low back pain.

The health plan sends its new MRI guidelines to its doctors. These guidelines indicate the types of medical problems for which an MRI test will be paid for by the health plan.

Do you believe that Happy Valley Health Plan should have guidelines like this?

Yes ___ No ___ Not sure ___

#3 Stay Well Health Plan

The directors of Stay Well Health Plan are looking for ways to improve health outcomes and use health plan dollars more effectively. One area that concerns them is that only 69% of women aged 50 to 75 receive breast cancer screening (mammograms) each year.

The health plan also learns that national studies show that routine mammograms for women who are under age 50 and over age 75 provide very little benefit, in terms of the number of cancers diagnosed and lives saved.

Stay Well discovers that if they stop covering routine mammograms for women under age 50 and over 75 – **and use those funds to increase the screening rate from 69% to 95% of all women age 50-75** – they can prevent more women from dying of breast cancer.

With the old system, when Stay Well provided 300,000 mammograms each year, 900 lives were saved over a 15-year period at a cost of \$700 million. With the new system, 1,200 lives will be saved for the same amount of money.

Although this means they will not pay for routine screening mammograms in women under 50 and over 75, they will still pay for mammograms for those who are high-risk or who have certain symptoms.

The health plan’s medical directors feel this new plan is a more cost-effective use of members’ dollars and ask for approval to begin. Would you support Stay Well’s plan to eliminate one service in order to do another, more cost-effective service?

Yes ___ No ___ Not sure ___

Appendix D

Consumer Telephone Survey, Results and Findings

Visible Fairness contracted with JD Franz Research, Inc. to conduct a random telephone survey of 500 persons in the four county region of Sacramento, Yolo, El Dorado and Placer. The purpose of the survey was to assess public attitudes about health care costs and cost containment strategies. While the questions are similar in theme to the Visible Fairness consumer discussions, the content of the telephone survey is broader and less detailed. Together, these two approaches provide a fuller picture of consumer perspectives.

Following the survey instrument and results are several observations about respondents’ views on cost containment and the trade-offs between cost and benefit. These observations were prepared by the Visible Fairness project leadership.

Sample Selection N = 517

The sample for the survey was a random digit dialing (RDD) sample designed to represent all households in the targeted area. RDD, the most sophisticated strategy for telephone survey sampling, ensures the inclusion of unlisted, erroneously listed, and newly listed households in the sample.

Area codes and prefixes in the Sacramento area for the sample were determined by Survey Sampling, Inc. (SSI), the nation’s leading supplier. SSI then randomly appended the final four numbers of a telephone number to these area code/prefix combinations by computer. The resulting numbers were printed out on call record sheets designed to facilitate full sample implementation.

In the introduction, respondents were told that this is a survey about the cost of healthcare (“we are going to be talking about healthcare policy, not about your personal healthcare experiences”). Respondents were then asked if there was anyone in the household who is a healthcare professional, such as a healthcare administrator, doctor, nurse or technician. Only respondents who said there was not were asked to complete the interview.

1. Based on what you know or may have heard, do you think health care costs in this country are:

<u>Increasing</u>	<u>Decreasing</u>	<u>Staying the same</u>	<u>Don't know / no opinion</u>
81%	1%	11%	7%

2. Are you very concerned, fairly concerned, not too concerned, or not at all concerned about the costs of providing health care in this country?

<u>Very</u>	<u>Fairly</u>	<u>Not too</u>	<u>Not at all</u>	<u>Don't know / no opinion</u>
55%	29%	11%	5%	<1%

3. Is the cost of health care for you or your family something you worry about a lot, somewhat, a little, or not at all?

<u>A lot</u>	<u>Somewhat</u>	<u>A little</u>	<u>Not at all</u>
30%	30%	18%	22%

4. There are a number of things that affect the cost of health care. Do you feel the following factors increase the cost of health care a great deal, some, or not at all?

	<u>Great</u>	<u>Some</u>	<u>Not at all</u>	<u>Don't know</u>
a. The development of expensive new medications	40%	44%	13%	4%
b. The increase in the number of older adults in this country	46%	36%	14%	2%
c. The availability of high-tech medical equipment and procedures	44%	44%	10%	4%
d. People who do not take responsibility for keeping themselves healthy	46%	36%	14%	4%
e. Health plans that care more about profits than about patient care	63%	26%	8%	4%
f. The advertising that drug companies do to persuade people to ask for name-brand drugs	43%	36%	17%	4%
g. Patients who insist on having the latest medical treatment even when their doctors say it won't help	34%	43%	16%	7%
h. Doctors who order expensive tests and procedures that do not provide much benefit to patients	45%	36%	14%	5%

5. Do you agree strongly, agree somewhat, disagree somewhat, or disagree strongly that _____?

	<u>Agree strongly</u>	<u>Agree somewhat</u>	<u>Disagree somewhat</u>	<u>Disagree strongly</u>	<u>Don't know</u>
a. Patients should pay more for their health insurance if they don't practice good health habits.	20%	33%	17%	24%	6%
b. If there is a new medical treatment that will help patients slightly more than another treatment, health plans should pay for the new treatment regardless of the cost.	47%	30%	11%	6%	6%
c. Drug companies should be restricted in how much they can charge for prescription drugs.	59%	24%	9%	6%	3%
d. Health plans should cover all advances in medicine even if this results in higher insurance rates.	31%	37%	16%	9%	7%
e. Patients should pay a greater part of their health care bill so they will be more cost-conscious.	12%	23%	23%	38%	4%
f. Doctors should be encouraged to follow medical guidelines on cost-effective ways to treat various medical conditions.	38%	34%	14%	12%	2%

6. Do you think this country is doing _____ to control healthcare costs?

<u>Too much</u>	<u>Too little</u>	<u>Just about the right amount</u>	<u>Not sure/don't know</u>
5%	70%	18%	7%

7. Do you feel _____ should take a lot, some, a little, or no responsibility for controlling the costs of health care?

	<u>A Lot</u>	<u>Some</u>	<u>A Little</u>	<u>No Responsibility</u>	<u>Don't Know</u>
a. doctors	35%	40%	13%	8%	4%
b. health plans	49%	32%	9%	6%	4%
c. government	43%	26%	14%	14%	3%
d. patients	38%	40%	13%	7%	3%

8. All health plans cover some treatments and medical procedures but not all treatments. Do you feel this is very reasonable, somewhat reasonable, somewhat unreasonable, or very unreasonable?

<u>Very reasonable</u>	<u>Somewhat reasonable</u>	<u>Somewhat unreasonable</u>	<u>Very unreasonable</u>	<u>Don't Know/no opinion</u>
9%	38%	32%	19%	2%

9. If a patient with a headache insists on having an expensive test to see if there is a brain tumor, even though the patient's doctor says the test is unnecessary, should the patient's health plan pay for the test, or not?

<u>Should</u>	<u>Should not</u>	<u>Other</u>	<u>Not sure / don't know</u>
40%	44%	8%	8%

10. If a patient with a heart condition insists on having bypass surgery even though the patient's doctor says that only medication is needed, should the patient's health plan pay for the surgery, or not?

<u>Should</u>	<u>Should not</u>	<u>Other</u>	<u>Not sure / don't know</u>
20%	65%	7%	8%

Demographics of Respondents

11. County of residence:

<u>El Dorado</u>	<u>Placer</u>	<u>Sacramento</u>	<u>Yolo</u>	<u>No response</u>
4%	11%	74%	10%	1%

12. Gender:

<u>Male</u>	<u>Female</u>
43%	57%

the health plans as the major contributor to cost problems, physicians view patients and society as the major drivers of inflation.

Patients and doctors as decision-makers

Questions 9 and 10. Forty percent of respondents said a health plan should pay for an expensive test for a patient, though the doctor says the test is not necessary. Only 20% say the health plan should pay for *surgery* for a condition that the doctor says could be treated with medication.

Comment: In the first example, the 40% reflects the not uncommon view that the wishes of the patient should be respected, even if the physician disagrees. Though 40% is less than half, it indicates that a substantial number of respondents do not know (or disagree with the requirement) that health plan coverage is limited to those interventions deemed medically necessary by a physician.

The lower support on the surgery question suggests there may be a limit to when patient wishes should supercede physician judgment. One could speculate that this may have to do with diagnostic testing being perceived as routine and low-risk while surgery is technically sophisticated and high-risk. MRIs and CT scans are so much a part of the popular vernacular that consumers may not regard them as interventions whose use requires medical expertise.

Attitudes about health plans' coverage policies and cost-control

Questions 5(b), 5(d), 7, 8, 9. Though many respondents want health plans to take responsibility for controlling costs (ranked the highest of the four groups listed, with 49% saying health plans should take “a lot” of responsibility), restricting coverage of medical treatment is not widely supported:

- 77% agree strongly/somewhat that, regardless of its cost, a treatment that works slightly better than another should be paid for by the health plan.
- 68% agree strongly or somewhat that all advances in medicine should be covered, even if this means that insurance rates go up.

- Half (51%) believe it is unreasonable for health plans to cover some but not *all* treatments.

Comment: These responses suggest that putting limits on health care coverage by health plans is not widely accepted. While respondents are concerned about rising costs, their willingness for health plans to pay for more services suggests that consumers have either 1) not made a connection between increased health care costs and access to new, expensive medical technology; 2) see the connection, but have a desire for comprehensive coverage that supercedes the desire to control costs; or 3) see the connection but believe that costs should be controlled in other ways than reducing coverage benefits. And with 63% indicating that health plans caring more about profit than patient care is a major contributor to cost increases (question 4e), many may believe that health plans should control costs by reducing their profit margin, rather than restricting what is covered.

The role of patients/consumers in cost-containment

Questions 4(g), 5(a), 5(e) and 7(d). Forty-six percent of responders believe that “people who do not take responsibility for keeping themselves healthy” increase the cost of health care “a great deal,” and 38% thought that patients should take “a lot” of responsibility for controlling the cost of health care. Yet only 20% agreed strongly that patients should pay more for insurance if they don’t practice good health habits and only 12% agreed strongly that patients should pay a greater part of their health care bill.

Comment: While respondents believe that patients contribute to the cost-escalation problem and that they need to take more responsibility to contain costs, their responses to other questions do not show a willingness to increase consumer cost responsibility. Respondents are more inclined to assign cost-containment responsibilities to other stakeholders, and they expect these actions can be done with little impact on coverage of new technologies. This expectation is counter to the increasingly common view of the health care industry that more financial responsibility will need to be borne by the individual consumer before costs can be controlled.

Appendix E

Visible Fairness thanks the following individuals for their many contributions to this project.

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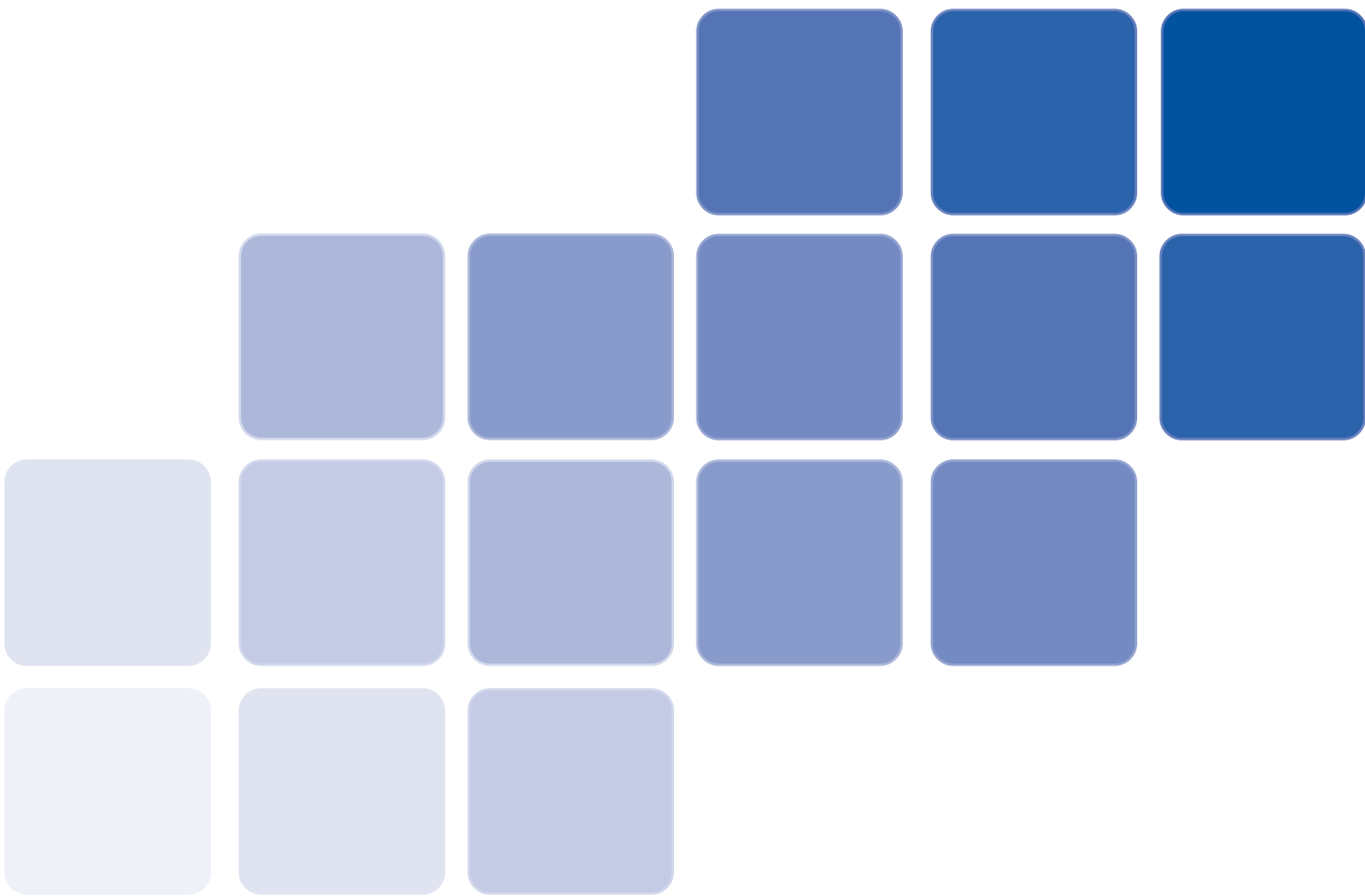
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