

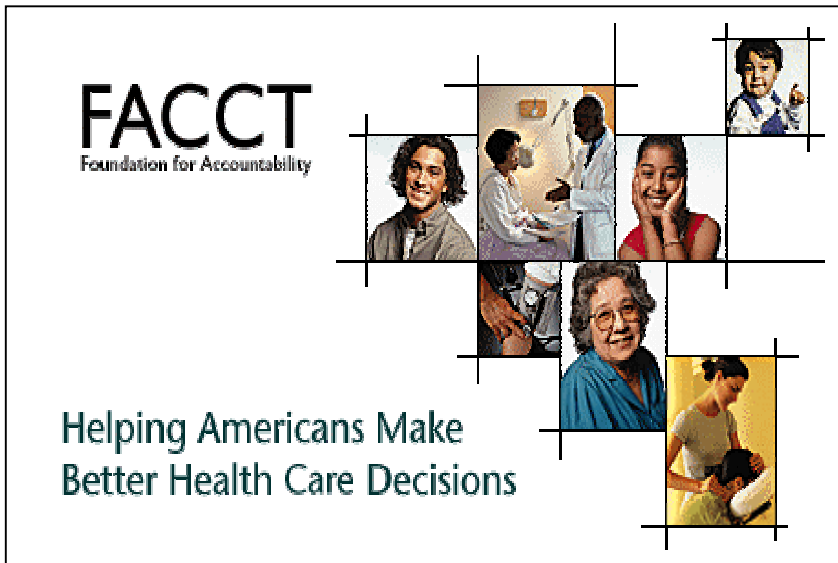


**Consumers and Quality  
What do they know?  
What do they want?**

**Results from FACCT Consumer Research  
1996-2000**

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## Consumers and Quality

*What do they know?*

*What do they want?*

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## Introduction

FACCT is a not-for-profit organization dedicated to helping Americans make better health care decisions. FACCT's work is driven by a desire to empower consumers, and through our research we have sought to listen carefully to consumers' values, needs, and experiences. Over the past four years we have studied:

- How consumers define quality health care.
- Who consumers hold responsible for assuring quality health care.
- What consumers expect from their providers.
- What information consumers want.

This report summarizes the findings from FACCT's archive of consumer research that includes.

- More than 85 **focus groups** with US consumers, including Medicaid and Medicare enrollees, commercially insured workers in both traditional and managed care plans, patients and parents affected by chronic illness, acute illness, and caring for terminally ill family members, teenagers, and a cross-section of ethnic and language groups
- **Online survey data** from more than 55,000 Americans about their health care and their information needs. These include 48,000 participants in the RWJF National Indicators Survey and 7,000 Fortune 100 company employees.

It is important to note that focus group research is qualitative and designed to provide insights into opinions and attitudes. By design, focus groups are conversations among small groups of people who, in sharing their thoughts, may influence one another, and who do not comprise a statistically reliable sample that can be projected onto a larger population. The online surveys represent a new methodology and are not necessarily generalizable to the adult population. Where appropriate and relevant, we have cited additional studies.

## ***Key Findings***

### **Consumers see their doctor as the single greatest determinant of quality.**

- A “good doctor” is defined as blending technical expertise with excellent interpersonal skills.
- Consumers want to be a partner with their doctor.

### **Traditional trust in the doctor and the health care system is eroding, and will probably continue to erode as consumers become more aware of poor quality in the system.**

- Consumers are uneasy about the state of health care. Trust in their physician to make the right decisions for them is waning.
- In one employee survey, 84% said they would prefer being treated by a doctor other than their own if at a safer hospital.

### **Consumers are beginning to seek outside information and use it to ask questions and make health care decisions.**

- The kinds of information and assistance most attractive to consumers are things that would help them choose a doctor or determine if their doctor is providing the right care for their specific needs.
- Consumers still are largely unaware of clinical indicators of quality or practice guidelines, but want them and would use them as a point of discussion with their doctor.
- Consumers are not a homogenous group. About one third use the internet for health care information. 20% are avid information seekers, regularly turning to the internet and magazines for information about their health care.

## Finding 1: For most Americans quality health care means having a “good doctor.”

**Quality most often is defined as having a “good doctor.”** Regardless of education level or condition, most consumers focus on their experience with the doctor, listing good and bad attributes of quality by describing what they seek from a physician.. They **do not seem to understand how a health plan specifically affects an individual’s care with the exception of choice of doctor and access to specialists.** Doctors are the central point of leverage in the health care system because:

- Consumers have direct contract with their doctor, which makes talking to their doctor easy.
- The doctor is the least intimidating to approach. It is difficult for many consumers to imagine taking on their insurance company or demanding that their employer become engaged in their health care.
- Many consumers see doctors as their best defense against bad care.

### Federal employee

“I had confidence in my doctor. And I didn’t want to change and go ... so I just **stayed where I was on the plan.**”

### ***Describe good quality care***

- Right doctor
- Doctor’s expertise/knowledge
- Caring/sensitivity
- Choices
- Follow-up
- Doctors who spend quality time
- Takes time with you
- Up-to-date technology
- Dedicated to patients

When probed to move beyond the physician experience in describing quality, individuals, particularly those with a chronic disease, add that **access to specialists and prescription drugs** define quality health care. Such answers likely reflect real life experiences for individuals and may vary by condition. A health rights hotline in California analyzed more than 1000 telephone calls to its hotline over a three year period. Callers with **cancer** were twice as likely to experience specialty care problems than the average hotline caller, while persons with **diabetes** were nearly three times as likely to report prescription drug problems—usually denial of coverage or uncovered costs.

### ***Describe bad quality care***

- Not enough doctors
- High turnover of doctors
- Long waits
- Misdiagnosis
- Lack of quality time
- Inefficiency/incompetence
- Arrogant
- Poor bedside manner

### Parents of Diabetic Children

- “Good quality is being able to contact the specialist whenever I need him/her by phone, fax, or office visit.”
- “Good quality is being able to get prescriptions for medications and supplies we need.”

**Finding 2: Consumers want a doctor to be technically competent and compassionate. More and more they are seeking a partnership relationship.**

**Consumers want a doctor experienced in their particular disorder.** In repeated focus groups, consumers want care from a physician or provider knowledgeable about current therapies, who involves them in decisions about therapy, takes the time to discuss their concerns, and takes their concerns seriously.

**Consumers' experience of care matters as much as technical aspects of care.** Consumers care about how they are treated personally—whether the doctor spends time with them and pays attention to them, whether they are treated with respect, and whether they can be seen quickly.

Adult Diabetes Patient  
Experience of care

“The doctor listens to me, answers my questions and gives me information about what he thinks is going on and what he proposes. Also asks if I have further questions or concerns.”

**Consumers recognize the importance of a partnership with the physician to achieve good results.** Several consumers stressed the importance of a clear, “plain language” communication style. Many saw this factor as the gateway to quality care—an effective relationship with an experienced provider. Women and consumers of color thought this was a more important indicator of quality care than did white men.

Adult Diabetes Patients  
Technical quality of provider

- Expert knowledge
- Identified problems/illness are treated accurately and expediently, problems without identity are tested logically and thoroughly so that correct treatment may be administered upon identification
- When my endocrinologist knows enough about my routine to suggest new and improved products and practices
- Doctor stays informed of current technology
- My doctor monitors all phases of my diabetes

Medicare Beneficiary

“Quality care to me is my doctor looking at me and doing what is effective to keep me moving so I can go out every day and do what I want to do. And my doctor does that.”

***I am satisfied with my health care because my doctor:***

“cares and is there for me.”

“has helped me in ways other than just physically. I trust my doctor.”

“takes time to ask me questions and really hears what i am saying”

“listens and responds (to me).”

“lets me participate in decisions about my care.”

“doesn’t dismiss symptoms or overlook my concerns—takes them seriously.”

“is considerate of my feelings.”

“takes time with me—i don’t feel rushed.”

“is there for me—i know my doctor will respond to my calls.”

“has current information—keeps up with new information and treatment options.”

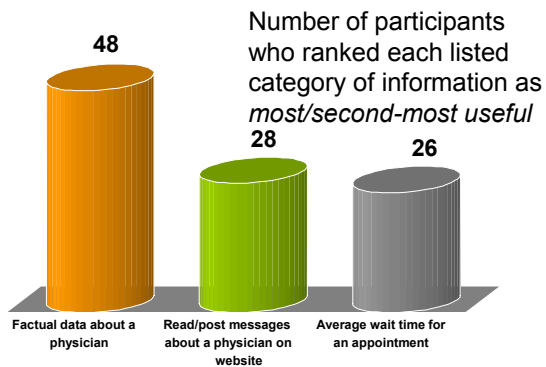
“is not afraid to refer me to others who may be able to understand the problem better.”

“knows what to do when problems occur.”

“follows through on (my) care.”

**Finding 3: While word of mouth remains the primary method for choosing a doctor, consumers are interested in factual information. Many use trial and error to find a good doctor.**

### Tools For Choosing A Physician



When consumers seek information on who is a “good doctor,” consumers most often ask friends and families for advice. When asked to list what factual information would help in choosing a doctor, consumers choose what is available today. Participants said important things to know were years in practice, malpractice record, and hospital affiliation. Less important was number of patients or medical school attended, often available in health plan or physician office marketing materials. Average wait time was not important; although this is a frequent question on patient satisfaction surveys. Many said they are used to a long wait and feel a “good doctor” is worth the wait.

#### Breast cancer patient

“And then I met my woman doctor who I’ve had for 19 years now. *She’s been a friend*—which is very important to me and has helped me in many ways other than just physically... She recommended the doctor who did my breast surgery.”

#### Breast cancer patient

“I thought it was important because when they got my test results back, my doctor called me up that night and talked to me for about an hour and that made me feel so good. My God, that’s terrific! You know, it gave me a lot of confidence that, boy, he’s going to take good care of me now. He told me anytime to call him and I really felt good because I was up here from Massachusetts and I was here alone and I thought ‘whoopie do! I found a good one.’”

Still even with the available information, many, and particularly those with chronic disease, expressed frustration at finding a doctor that met their needs. Many considered finding a “good doctor” luck. A few, especially those with serious diseases, self-educate themselves and then through painful and dangerous trial and error find a doctor that meets their need. Regrettably, it is this trial and error process that consumers often say makes them effective advocates for their own care.

#### HIV/AIDS Patient

“Doctors don’t usually discuss [many of the side effects] with the patients when they try them on [a new therapy], especially when they are failing with one therapy. They say, ‘Well, we will put you on this.’ Well, I’m fortunate that I have two doctors that are very proactive about my health, but unfortunately I’ve had to educate myself to finding those doctors.”



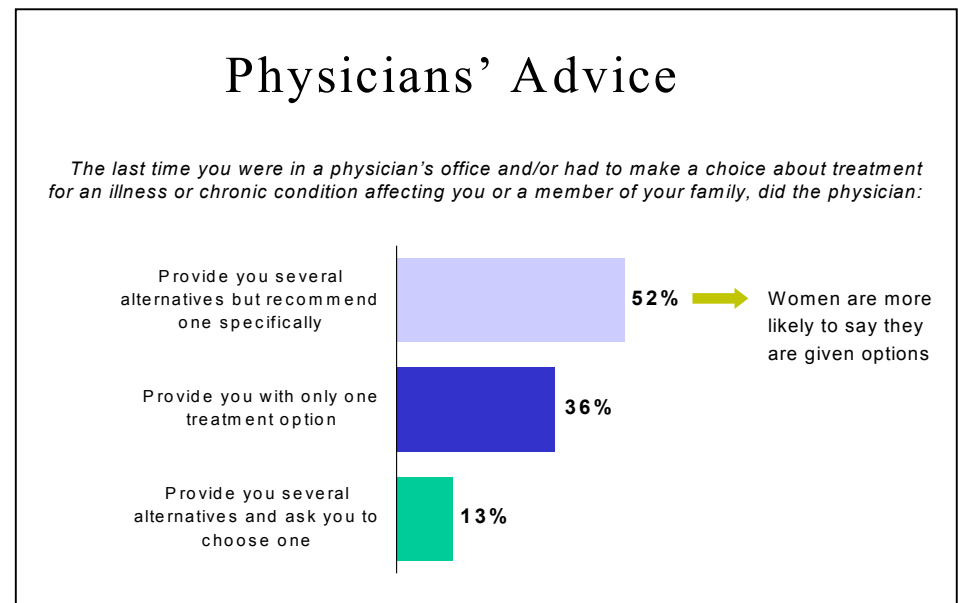
**Finding 4: Once they find a “good doctor,” the majority continue to rely heavily on their physician to spell out and make sense of treatment options. As medical information becomes easily accessible, others are taking a more active role in decision-making.**

Consumers think it is important to be offered an informed choice between therapies—they wanted physicians to thoroughly discuss alternatives and potential side effects. If faced with a serious decision or health problem, many consumers in a national online survey stated they would seek a second opinion. However, when this same question was asked to focus group participants, **many added that the second opinion was to confirm a treatment rather than to question it**

Thinking about the experiences you have had with health care professionals, such as doctors, please tell me how likely or unlikely you are to do the following:				
	VERY	SOMEWHAT	NOT VERY	NOT AT ALL
Get a second opinion on a serious diagnosis	65%	25%	6%	5%
Look up information on a new prescription such as side effects and precautions	61%	23%	11%	5%

In general, consumers follow their doctor’s advice. In a survey among employees from a Fortune 100 company, three out of five consumers said they simply follow what their doctor advises. The remainder say **they play an active role in making treatment decisions**, but half of these make decisions on the spot, while the others deliberate for a longer time. Men were most likely to follow their doctor’s advice.

A key here appears to be the discussion of options. **If offered alternative treatments from their physician, participants said they are significantly more likely to evaluate their options and not simply defer to their physician.** However, to evaluate alternative treatment options, three in four turn to their physician for additional advice and information. Other studies that suggest that most Americans want to be informed about their health but less than half actually feel confident in understanding the health information they read.



**Finding 5: Consumer trust in health care institutions and physicians is eroding. They believe that those who have the ability to ensure quality do not always have an interest in ensuring quality. They conclude that they must take such responsibility.**

Consumers do not trust typical sources of information on health care quality. In a series of focus groups conducted in 1999, the sense among the participants was that:

- Health care companies are motivated by profits, and if forced to choose between quality care and saving money, most would choose saving money.
- Employers, like health care companies, are motivated by money, not by the well-being of their employees.
- Government rarely acts in the interest of consumers when powerful lobbyists are pushing in the other direction.

Federal employee  
 “I don’t know how true it is but there’s supposed to be something charged against the doctor’s account if he sends you to a specialist.”

Even the doctor is under some mistrust because of changes in reimbursement. A VHA survey in 1999 found that consumer trust in physicians had dropped 23% since 1994.

110 FACCT focus group participants in 1997 rated several sources for information on quality (see sidebar). The increasing use of the Internet for health care information was not asked in this study

How believable about quality?	Very believable
Individual doctors	48%
Friends and families	41%
Patients who have been surveyed	40%
Independent organizations	22%
State medical societies	17%
Health plans	15%
Employers	11%
Government agencies	6%
Media	2%

N=110

but there is evidence it is a growing source of information. Thirty-one per cent of employees at a Fortune 100 company said they either regularly read or subscribed to a health care magazine or were **registered** on a health care web site.

In the end, most participants in focus groups concluded that the answer to the question, “Who is responsible for assuring quality?” is that they are. When asked how they could do this, the answer was to choose a “good doctor,” which is one of the few things they can choose and one of the few parts of the system they can influence. **But many were frustrated because they did not know how to find one.**

Asthma Patient  
 “Good doctors are everywhere, bad doctors are everywhere, I need to find what’s right for me.”

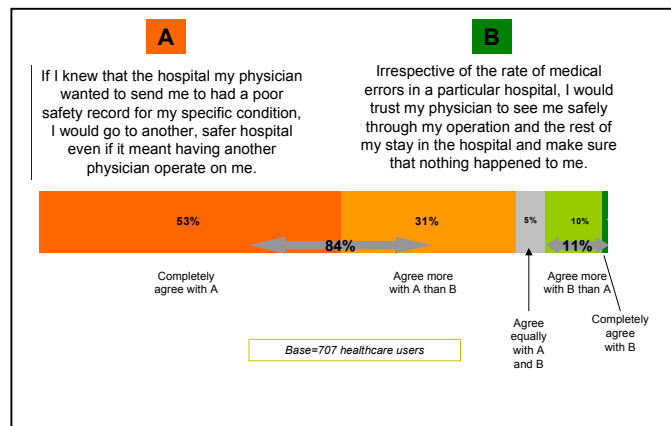
**Finding 6: Consumers increasingly are aware of health care errors and poor quality; most would change their doctor if they felt their safety was in jeopardy.**

When FACCT started conducting focus groups in 1996, consumers generally felt that health care quality was pretty much the same everywhere and that the doctor insulated them from bad care. Most focus group participants today believe that quality of care varies, and often significantly. It is hard to tell whether this is from personal experience, news stories, or the entertainment media, but the overall impression from focus groups is that consumers are uneasy about the state of health care. These concerns were confirmed in a 2000 online poll of adults.

Adult

If a doctor is good, he'd associate with a better hospital. So I don't have to do much decision-making."

Do you think there are big differences, small differences or no differences in the quality of health care among?			
	BIG	SMALL	NO
Hospitals	40%	41%	19%
Health plans	50%	34%	16%
Family doctors, general practitioners or other primary care doctors	39%	41%	20%
Specialists	38%	41%	21%



When questioned about patient safety, 84% of employees in a Fortune 100 company said they would prefer being treated by a doctor other than their own in a safer hospital. Only one in ten would rather stay with their physician even if it meant being treated at a less safe hospital.

**Finding 7: Consumers want to make good choices but most remain unfamiliar with clinical indicators of quality. Once introduced to them, many say they would use such information to find a “good doctor.”**

Most focus group participants at first had difficulty describing any clinical dimensions of quality care. Once they were presented with examples, participants were interested in getting this information to evaluate their care. This has been a consistent finding in all of FACCT’s focus groups. Moreover, they want more than one or two indicators and measures that reflect a composite of quality information— experience of care, symptom control and outcomes. Consumers with specific diseases want information that is relevant to their disease.

Good quality is “when you don’t die.”  
Bad quality is “he became paralyzed and he eventually died.”

Most believe strongly that outcomes are important measure of quality care, but their outcomes were extreme, death or serious injury. When we asked consumer and medical experts to list quality of care for key diseases we found disagreement about what are important measures of quality. Consumers are less likely to choose process measures or measures that they view as primarily the

Federal employee  
“I think that (results) would really make a difference in helping people select and then would also give the providers a message that folks are looking at their outcomes.”

responsibility of patients or society. There was little or no interest in plan measures.

- “I’ve always considered injury prevention more common sense.”
- “You can get this kind of advice on TV and radio. It is widely available.”
- “An average adult should know these things anyway from so many other sources, even if the doctor does not mention them.”

Consumers are leery about too much data and stated they want simple, easy-to-understand information. As a result of early focus groups, FACCT developed the Consumer Information Framework, which groups measures and data into consumer-friendly categories. The Basics, Staying Healthy, Getting Better, Living with Illness and Changing Needs. This framework has been endorsed and used by numerous health care stakeholders, including NCQA, the major auto manufacturers, major employers, *Newsweek* magazine, and numerous state governments (i.e., Connecticut, Maryland, Florida, Michigan, Washington).

**Finding 8: Consumers are unaware of practice guidelines; research shows that many physicians do not follow them. If armed with evidence that their physician is not following standard care, consumers will begin to demand accountability.**

Consumers generally are unaware of best practices or national guidelines. Most physicians do not follow them, despite nearly a decade of research and demonstration projects to increase physician adherence to guidelines. Consumers thought the guidelines were extremely useful..

Fortune 100 Company employee

“I’d still want to know why isn’t that physician following it? If I had asthma and was considering going to this person, the questions I would ask to that physician are: ‘Why aren’t you following the best practices, and tell me why what you’re doing is acceptable?’”

When presented with treatment that conflicted with best practices, participants were uncomfortable. While some were willing to give their doctor the benefit of the doubt, nearly all said they use such information in discussions with their doctor.

Fortune 100 Company employee

“My guess is it would be an advantage to us to know what the best practices are because if we go to a physician, and they’re not following it, we know it’s a standard. We can say, ‘Hey, why aren’t you doing this or why are you doing this?’”

The caveat is that most consumers do not regularly seek out health care information. Segmentation studies of the adult population suggest that about 20% of consumers enjoy reading about health, look for information on the internet or subscribe to the health care

magazines. The rest to various degrees will read information only if it is available, and there is personal interest. They generally do not enjoy reading about health, and they are not confident in the information they find. In general, the trigger for most of the population to seek information is around the diagnosis of a serious illness. The most passive health care participants are older men with lower than average incomes, while the most aggressive information seekers are women with higher than average incomes. The former acquiesce to the physician; while the latter ask questions, discuss all options with their doctors, seek out relevant health care information and feel they ultimately make the health care decision.

FACCT’s studies into focus group messaging found that to make health care personal and relevant for most consumers will require communicating risk. **People need to feel the danger they may be facing if they are not more alert and responsible about their health.** Benign, positive, ‘improvement’ messages do not motivate most consumers to pay attention to the health care information.

## **Overall Finding**

We have summarized the findings from more than 85 FACCT focus groups and two online surveys. In addition we have used other research to test our findings. Health care is an issue with enormous personal relevance to many people, and it raises strong emotions. In FACCT's focus groups, as well as in opinion research, it is clear that consumers are both frustrated and fearful that they are at risk for inadequate care, and yet they are without the ability to assess and demand quality in their own lives.

Our research about quality leads us to focus on the physician/patient relationship, which for the consumer is the nexus to the health care system. Consumers believe that their doctor controls the quality of their health care, and they traditionally have placed much trust in their physician to make the right decision for their care. We see growing stresses on the doctor/patient relationship and an opportunity for Novartis to help restore that trust, but not by trying to reestablish an outmoded and inadequate type of relationship. The VHA survey in 1999 found that trust in physicians had dropped 23% within a five year period. During FACCT focus groups, consumers are expressing concern about quality. They are afraid that medicine has become commercialized, focusing on the "bottom line." Their concerns are matched by many physicians who feel that they practice in an environment of unrelenting pressure to reduce costs and avoid litigation.

Many health care leaders believe that increased consumer involvement will change the system, restoring the balance between cost and quality. But today consumers still lack the information and tools (and financial incentive) to have any meaningful influence, and there is much resistance by the medical community to change. We do not think that physicians can afford to ignore the stresses on the doctor/patient relationship nor the demand for more participation by consumers in their health care.

Health care information and tools to evaluate quality will become available rapidly. The number of e-health sites has risen sharply in the last two years, generating huge traffic to the sites. But perhaps the largest distributor of health information will become the private purchasers of health care. In the next five years, Americans will be exposed to more health care information in the workplace than ever before. Large employers and unions are becoming vehicles for health care information combining wellness and disease management with benefit information. A number of e-health companies are directly marketing to the employer with the promise to reduce health care costs through better management of high users and a more-informed workforce. Partially driving this corporate interest is the prospect of defined contribution benefit plans where employees will be able to direct where their health care dollars go and have a direct financial incentive to make informed choices. While still in the infancy stage, e-health companies are rating physicians and are enhancing their tools almost daily. Some are integrating national guidelines into the tools as a method for evaluating quality. All this suggests that physicians will be increasingly held accountable for the quality of the care they provide.

## ***Recommendations***

Based on this research, we believe there are a number of opportunities to consider:

- Support strategies for empowering the consumer
- Support or partner with other organizations in their strategies for empowering the consumer
- Support strategies for preparing the physician for increased consumer involvement
- Support research on consumer-centered health care

### **CONSUMERS**

- Provide guidelines to consumers/patients, create pocket cards, e.g., 10 things you need to know to get quality care for diabetes
- Provide help in communicating with MD, including personalized tip sheets, preparatory questions
- Provide non-controversial help in how to find the right doctor for you
- Create resources to guide consumer information, e.g., web portal that tells people which content is sound and which not
- Use DTC and other consumer communications to send messages about appropriate use of medications, compliance, supporting physician's intent.

There is a wealth of health care information available on the internet and from other resources. While some sites are pedantic, others are consumer-friendly, easy-to-use and informative. They clearly appeal to the 20% of the population that seek out health care information. The challenge for this segment is to provide concrete tools or steps that motivated health care consumers can take to assure they are getting quality care from their physician. We believe such information should be concise and tied to standard treatment protocols (pocket cards that list the 5 or 10 things to ensure you are getting quality care) and physician ratings.

To reach the rest of the population with information about quality will require more extensive marketing. Our testing suggests that the most effective messages tap consumers' fears about health care and their cynicism about the politics of health care—the frightening consequences of not paying attention, and the need for the consumer to take responsibility for finding quality care.

## OTHER ORGANIZATIONS

- Support Leapfrog in developing its 4<sup>th</sup> leap aimed at ambulatory care or a specific condition for patient safety
- Support FACCT by providing marketing and clinical expertise to its internet tools.
- Work with other pharmaceutical organizations to create responsible safety conscious image

## PROVIDERS

- Develop or secure the rights to a patient screening instrument to help define doctor/patient decision-making styles. Using an instrument (or a reduced version) such as The Patient-Practitioner Orientation Scale as part of the first office visit could help define the patient's and physician's preferred decision-making style. The scale combines two dimensions of patient-centeredness. The first perspective is concerned with the practitioner's interest in or willingness to understand patients' lifestyles and to explore psychosocial issues with patients. The second perspective is concerned with the practitioner's attitudes and behavior in relation to shared decision making. A study about the PPOS in *Patient Education Counseling* 2000 Jan;39(1):49-59 found that patients were most satisfied when their physicians either had a matching orientation or were more patient-centered.
- Publish a physician-briefing series on patient/provider relationship beginning with a shortened report. Do it both on scientific merit of patient-centered care and on practical things you can do for your patients; use IHI idealized practice design, etc. Two other topics might be an analysis of doctor ratings sites on the Internet and a summary of segmentation studies of health care information seekers.
- Advocating for increased and efficient use of communication tools as well as highlight successful practices that are using this email. Communication is an integral part of patients' satisfaction with and trust in their doctor. Physicians have been reluctant to embrace e-mail although it is increasingly becoming the most common way to communicate in this society. Daniel Sands article in the December 1999 Issue of *The American Journal of Managed Care*: Electronic Patient-Centered Communication: Managing Risks, Managing Opportunities, Managing Care, discuss why doctors are wary of this use.
- Help doctors understand their own patients; organize events in a market where patients meet doctors and talk about their experiences – like Healthpartners' diabetes event, or patient reunion (heart surgery patients, breast cancer survivors) but structure it to increase mutual understanding.



## RESEARCH

- Support qualitative research in the following areas:
  - a. doctor/patient communication—sustaining the trust
  - b. patient safety messages—how should doctors respond
  - c. e-health ratings—how to react, how to increase ratings

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Appendix 1: Focus groups 1996-2000

Audience	Location	Purpose	Year	# of gps.
General adults	FL, OR	Framework	1997	7
Breast cancer	FL	Framework	1997	2
General adults	WA	Framework	1998	1
Elderly	FL	Framework	1998	4
Federal employees	CA, CO	Framework	1998	10
Breast cancer	OR	Internet tool	2000	1
CAD	OR	Measure	1996	2
Breast cancer	OR	Measure	1996	2
Asthma	OR	Measure	1997	2
Parents of children age 6 and younger children with chronic condition	IL	Measure	1997	1
Parents of children age 6 and younger, health children	WA	Measure	1997	1
Parents of adolescents	CA	Measure	1997	2
Adolescents with chronic health condition	OR	Measure	1997	2
Depression	FL	Measure	1997	1
Diabetes	WA	Measure	1997	2
Parents of children with diabetes	CA, WA	Measure	1998	2
Alcohol (Family members and individuals)	WI	Measure	1998	2
Diabetes	WA	Measure	1998	2
HIV/AIDS	CA, OR	Measure	1999	3
End-of-Life (Caregivers and patients)	CA	Measure	1999	4
General adults	NY, CA	Messaging	1999	2
Parents of children	CA	Messaging	1999	2
Parents of children	CA, CO	Messaging	1999	8
Employees	OH	Messaging	2000	6
HMO enrollees	FL	Report card	1998	2
Commercially Insured	MN	Report card	1999	4
Commercially Insured	IO	Report card	1999	2
Medicaid	IO	Report card	1999	2
Fee for Service	IN	Report card	1999	1
HMO enrollees	IN	Report card	1999	1
Federal employees	TX	Report card	1999	2