Engaged Consumers

IN HEALTH & HEALTH CARE

INSTITUTE FOR THE FUTURE • HEALTH CARE HORIZONS

MARCH 2003 • SR-783

Engaged Consumers in Health & Health Care

Health Horizons Program

March 2003

SR-783

About the Institute for the Future

Located in the heart of Silicon Valley, the Institute for the Future (IFTF) is a not-for-profit research organization with over 30 years of experience in long-term data-based forecasting. IFTF identifies future trends and key discontinuities that will transform the marketplace. We provide key foresights and guide our members in drawing insights as input to their strategy, as well as possible action steps. Through the exploration of possible futures, we help companies, government agencies, and private foundations make better decisions in today's uncertain world.

Acknowledgments

AUTHORS:	Katherine Haynes Sanstad, Rod Falcon, and Susannah Kirsch
CONTRIBUTOR:	Leah Spalding
EDITOR:	Mary Cain
COPY EDITORS:	Jean Hagan and Pete Shanks
ART DIRECTION:	Jean Hagan
PRODUCTION AND GRAPHIC DESIGN:	Adrianna Aranda and Robin Bogott

This project could not have been completed without generous contributions of time and wisdom by the individuals who participated in health decision-maker interviews, and by the health care and consumer experts. This research is also deeply indebted to the many years of qualitative research conducted on the changing realm of the household by IFTF colleagues.

Contents

List of Figures and Tables

List of Figures and Tables (continued)

Executive Summary

Health care industry pressures and the realities of individuals' daily lives are driving us toward a health market in which consumers are more engaged in health care. While the industry is aggressively promoting incentives to increase consumer responsibility, individuals themselves will define their interests in the health domain and how to pursue them. The recent resurgence of health consumerism combined with consumer and industry drivers will shape how consumers engage with health care over the next decade.

Health is one facet of household life on which individuals spend time, money, and attention. Individuals create ecosystems of resources and practices to manage their health and the health matters of their families. These "personal health ecologies" help the individual navigate and manage their personal health domain.

Engaged health consumers are those individuals who are active in their health and health care and act consciously to further their own health interests or those of their loved ones. Our measure of engagement is one that focuses on health behaviors.

These engaged consumers define health broadly and, as a result, participate in a wide variety of activities and rely on a whole range of resources—within and outside the health care system—to manage and affect their health and well-being.

According to the health engagement index established by the Institute for the Future (IFTF), the hallmarks of the engaged health consumer are the desire for multiple perspectives on important health questions, engaging in regular and frequent activities to optimize health, and identification as a health decision-maker in the household.

THE FORECAST AT A GLANCE

Over the next decade, several factors will drive an increase in consumer engagement in health, while others will slow the pace of change.

Drivers and Barriers

Five consumer and industry forces will drive the growth of consumer engagement in health over the next decade:

- Increased consumer out-of-pocket spending on health care.
- Increased consumer attention to health issues because of the effects of aging.
- Lack of consumer trust in health care.
- Increasing access to health information.
- Industry efforts to control health care costs by shifting cost and responsibility to consumers.

Taken together, these forces have the effect of increasing consumers' stake in the value of the health goods and services they receive and compelling them to look out for their own best interests.

The rise of consumer engagement will not go unopposed. There are many obstacles along the way:

- Consumers may rebel against having new responsibilities for health and health care decisions and costs.
- The complexity of health and health care obfuscates rational consumer decision making.
- Health care organizations may be unable to deliver consumer-centered services.
- Inequities in the insurance markets may affect middle class workers and the elderly and provoke regulatory action.

Consumer Engagement: 2012

With these drivers and barriers in mind, we forecast that there will be a slow rise of consumer engagement. The pace at which health goods and services fall into place to support consumer engagement will determine the force and influence of engaged health consumers in health markets. We forecast:

- Engaged health consumers will grow from 33 percent of the population today to 41 percent in 2012, and they will be a mix of old and young, wired and those who don't use computers at all.
- The management of health in the household will grow increasingly complex, driving consumers to look for services and informal networks that help them simplify it.
- Engaged consumers will push the health and health care system to get what they need, and will make it known if their needs are not met.
- Health care stakeholders—plans, providers of health goods and services, and purchasers—will expand their focus beyond business-to-business efforts to incorporate an increasing facility to operate in business-to-consumer markets.

IMPLICATIONS OF THE EMERGENCE OF ENGAGED HEALTH CONSUMERS

The shifting role of consumers will affect all of health and health care in America and has implications for patients and their advocates, health care providers, health insurers, purchasers and policymakers.

Consumers, Patients, and Their Advocates

As consumers and patients are required to understand, decide among, and pay for their options for insurance, plans, providers, and treatments, they will have to learn about the complexities and costs of health and health care. For engaged consumers to succeed they will need to:

- Face trade-offs in cost and quality head-on.
- Secure trusted advisors in their personal health ecologies.
- Advocate for the right tools to make informed decisions.

Providers

As consumers make decisions between allopathic and alternative care, and reimbursed care and out-of-pocket payments, they will weigh the trade-offs of risks and benefits and begin to ask questions about efficacy and cost. Providers must prepare to respond by:

- Building responsive systems that support consumers.
- Talking straight about price and quality.
- Becoming coaches and interpreters for engaged consumers.
- Working with personal health ecologies to optimize care.

Plans

With information and tools to manage information, plans can succeed at aiding consumer engagement by:

- Making consumer-directed plans consumer-centered by:
  - Making it easy for consumers to see the value that they get from managing their own health benefits.
  - Making trade-offs in price and quality and convenience explicit.
  - Making consumer-directed plans work with existing benefits tools and resources.
  - Realizing that lots of consumers are reluctant to manage benefits online and providing enough flexible tools so that consumers can customize what they want in ways that fit with their lives and values.
- Helping consumers see trade-offs and simplify decisions.
- Helping to map the middle ground between defined benefit and defined contribution.

Purchasers

Purchasers want to share more responsibility and cost increases with an unsure consumer population. To avoid potential disruption and backlash purchasers could:

- Build systems with engaged consumers.
- Drive the market to deliver information to support consumers.
- Structure benefits options to maximize the advantages of group coverage.

Policy

Key policy issues on the path to greater direct consumer engagement in health and health care are:

- Promoting the availability of standard information on health and health care.
- Fostering health and health care literacy.
- Planning for high- and low-risk pools.
- Anticipating and providing for growth of the uninsured population.

Introduction

In these days of rapidly rising health care costs and retreat from tightly managed systems of care, many health care theorists and business leaders believe that greater consumer involvement in health care decisions and financing is the answer to controlling health care costs and, to a lesser extent, to improving quality. They advocate more consumer responsibility by asking consumers to pay more for the health goods and services they use. Some believe that paying more will give consumers the incentive they need to make rational and value-based decisions, which will bring about better products and services at better prices by setting true market forces in play. Are consumers the answer? Can they fix health care, and what do *consumers* think about assuming more responsibility in health and health care decisions and financing?

Consumerism in Health Care Is Not New

The drumbeat of consumerism in health care has been with us for some time. In 1989, David Mechanic wrote of the challenge of rational consumer decision making in the medical marketplace.[1] By 1996, the proponents of health care consumerism had grown so active that the journal *Health Affairs* dedicated an entire issue to exploring the implications of market-driven insurance on the role of the consumer.[2] The terminology has changed over time. Talk of defined contribution has been reframed in terms of defined care, and consumer-directed or consumer-driven health care.[3] Health consumerists were so sure that consumerism was the answer to the woes of the third-party-payer health care system that their critics were prompted to caution them against raising consumers to an exalted position without providing the information and decision-support tools necessary to foster rational consumer behavior.[4]

From Indemnity to Managed Care and Back Again?

Since 1988, health insurance has migrated from an indemnity world to a world of managed care. In 1988, 73 percent of insured employees were covered by indemnity insurance; by 2002 only 5 percent were.[5] Health care evolved from conventional insurance, in which consumers bore significant administrative burdens and unpredictable costs, to managed care, in which administrative burdens persisted for most consumers, but costs were infinitely more predictable. It was a shift from a world in which people sought only acute care coverage to one in which they expect acute, preventive care, and prescription drug benefits. The ascendance of managed care markedly slowed premium growth, but spurred provider and consumer rancor along the way. Employer-purchasers, who had sustained 18 percent premium growth in 1989, saw that growth slowed to less than 1 percent in 1996.[6] Yet by the mid-1990s consumers and providers began to bridle against the very factors that made consumer costs predictable and reined in premiums: restricted access to specialists and treatments, and discounted provider reimbursements. Even though most consumers were relatively happy with their own health plans, a managed care backlash emerged that was fueled by lack of choice, negative media coverage, and attention to rare negative events.[7,8,9]

Consumers migrated to insurance options that granted them greater choice. For many consumers, choice is a proxy for quality. Notably, enrollment in the more costly and flexible PPOs nearly doubled between 1996 and 2002, growing to 52 percent from 28 percent, while HMO enrollment declined.[10] HMOs themselves began to loosen restrictions. These moves, combined with the relentless upward cost pressures of medical technology, aging, hospital and drug costs, and insatiable consumer demand for health goods and services, reversed premium trends.

Consumers pursued choice and paid more for it—well, a little more. While many consumers had higher co-pays with PPOs, they didn't have to pay the real marginal cost. Their employers did that. When premium growth began to climb in the late 1990s, the economy was booming and employers gladly footed the bill because they needed to attract and retain workers.

Understanding the Role Today's Health Consumers Will Play Tomorrow

As the health care industry experiments with models it dubs "consumer-directed" and as employer-purchasers shift rapidly rising costs to employees, individuals have their own values and ideas about how to pursue health. How these notions of health and health care fit with current industry moves toward health care consumer models in which individuals exercise more choice and discretion but pay more and assume greater risk and responsibility is unclear. Will there be disruptive changes in how individual consumers participate in health care or continued incremental change at the margins of health care? Where do health and health care fit in the context of people's lives? And what are the implications for the providers of goods and services that compete in the health marketplace? These are the questions that drove IFTF to revisit its 1998 research on new health care consumers.

Why revisit health consumers now? Kaiser Family Foundation and Health Educational Resource Trust found that employer premiums rose at a rate of 13 percent overall in 2002, while Mercer Human Resources Consulting reported a 15 percent increase in health benefits costs for 2002 and projected similar

growth for 2003.[11] This is startling when you consider that in 2002 the overall economy grew at a rate of only 1.2 percent. The last time health care expenses grew at close to this rate was 1988; then, purchasers turned to managed care for solutions.

An estimated 1.5 million people are enrolled in emerging insurance plans designed to ensure that enrollees pay for more choice and more costly services. What's more, consumers themselves seem conflicted about taking on more responsibility for health care; consumer surveys show that they want more choice but no less service from employer-purchasers in negotiating insurance coverage and creating provider networks. At a time when Americans have come to expect benefits to cover the lion's share of traditional Western medical costs, nearly 68 percent of them have used alternative medicine, and most pay for it out of pocket.[12] As the health care industry seeks to shift costs and responsibility, our research on changes in American households suggests that consumers are already overloaded by the growth of information available to make household decisions, from what cell phone service to get to what assisted living situation is right for elderly parents. Can individuals become the health care consumers that health care industry theorists seek, in addition to playing all the roles they play in daily life?

In this report, *Engaged Consumers in Health & Health Care*, our aim is to get into the hearts and minds of consumers, to understand how they view health and health care, what they do to pursue health, the value they seek from health goods and services, and whether these values are in sync with the shifts now under way in health care. We begin with a look at health in the context of consumers' daily lives and how the demands of daily life shape consumer health needs. We then offer a forecast of the growing effect of engaged health consumers—those who actively participate in health and act consciously to further their own health interests or those of their loved ones. Finally, we explore the implications that the rise of engaged health consumers holds for health markets and for consumers themselves.

Endnotes

[1] Mechanic, D. Consumer Choice Among Health Insurance Options. *Health Affairs* Spring 1989.

[2] Iglehard, J. The Role of the Consumer. *Health Affairs* 1996; 15,4.

[3] Gabel, J., et al. Consumer-Driven Health Plans: Are They More Than Talk Now? *Health Affairs*, Web Exclusive, www.healthaffairs.org. November 20, 2002. Project Hope, 2002.

[4] Herzlinger, R., *Market-Driven Health Care*: *Who Wins, Who loses in the Transformation of American's Largest Service Industry.* New York: Addison-Wesley, 1997. Robinson, J., Apotheosis of the Health Care Consumer. *Health Affairs* 1997; 16,6.

[5] Family Foundation and Health Research and Educational Trust. *Employer Health Benefits, 2002 Annual Survey*. Publication # 3251. Menlo Park, CA: Kaiser Family Foundation, 2002.

[6] Gable, J., et. al. Job-Based Health Benefits in 2002: Some Important Trends. *Health Affairs* 2002; 21,5.

[7] Gawnde, A., et. al. Does Dissatisfaction with Health Plans Stem From Having No Choices? *Health Affairs* 1998; 17,5.

[8] Blendon, R., et. al. Understanding the Managed Care Backlash. *Health Affairs* 1998; 17,4.

[9] Brodie, M., et al. Media Coverage of Managed Care: Is There A Negative Bias? *Health Affairs* 1998; 17,1.

[10] Mechanic, D. Consumer Choice Among Health Insurance Options. *Health Affairs* Spring 1989.

[11] ibid, and: Employer-Sponsored Coverage: Higher Costs Force Workers to Pay More. *American Health Line*, www.nationaljournal.com. December 9, 2002.

[12] Kessler, R., et. al. Long-Term Trends in the Use of Complementary and Alternative Medical Therapies in the United States. *Annals of Internal Medicine* 2001; 135,4.

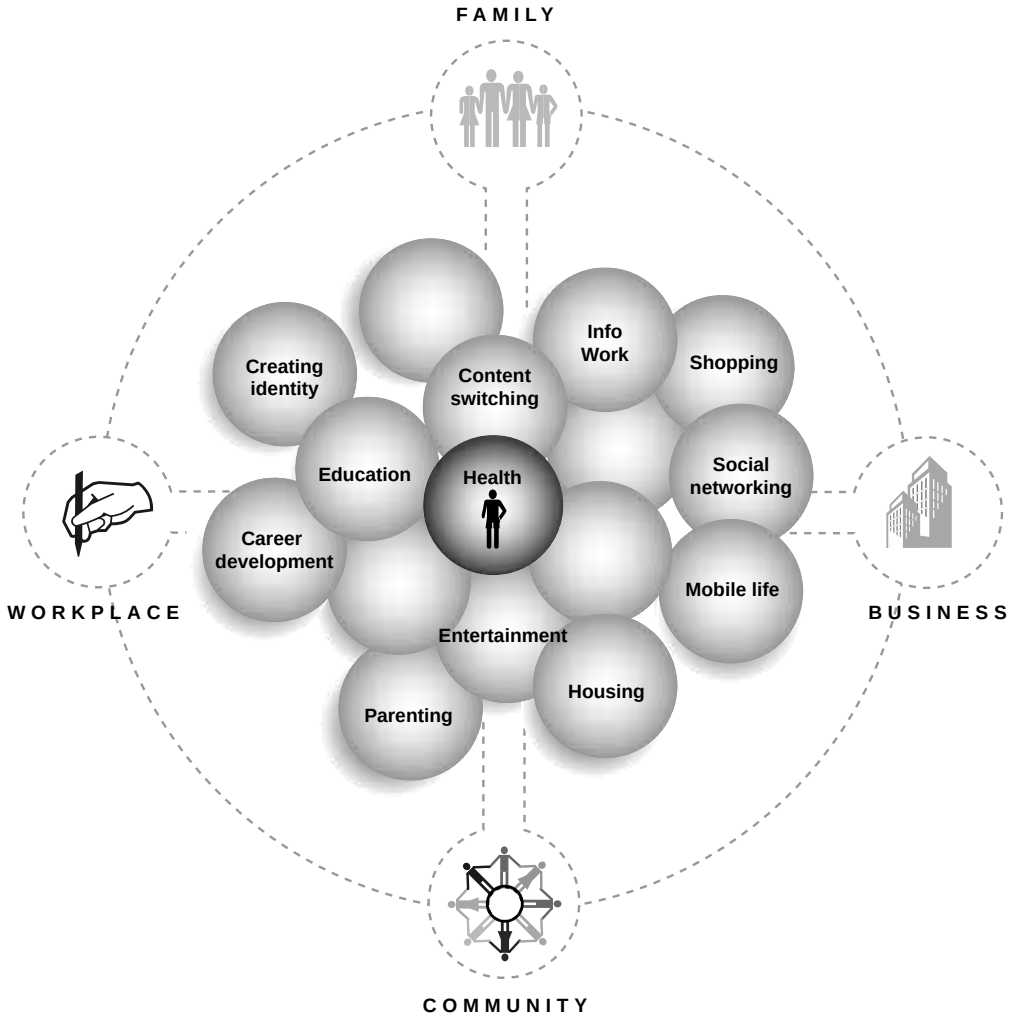
Chapter 1

Health: One Domain of Daily Life

The household is a hub of activity, relationships, and connections that shape our daily lives. It is the most fundamental social and economic unit, tying us to family, work, community, and businesses. With increasingly porous boundaries, growing diversity, and expanding realms of responsibility, the household is a conduit of information and resources and the organizing unit for purchasing decisions. While the physical location in which people manage daily life is becoming less fixed (for example, people negotiate plumbing contracts via e-mail from work), the household, as a family or collection of individuals, remains a crucial conceptual and organizational unit that affects how individuals act in the world.

Health is but one of the many realms of activity on which individuals spend time, money, and attention in their daily lives. Individuals juggle health along with their own or their family's education, finances, recreation, and housework. Each area of activity represents what we call a domain of daily life. The domains of daily life represent key areas of need that drive demand for new goods, services, and solutions, in health and all other domains. What consumers buy, what they value, and what products or services are useful and meaningful to them can be determined by investigating the domains of daily life. The practices individuals use to manage daily life have undergone and will continue to undergo tremendous transformation as the technologies, products, and services at their disposal expand. At the same time, the decision making process in each domain will continue to become more information intensive, often requiring consumers to exert great effort in finding, filtering, and evaluating information before acting (see Figure 1–1 on page 10).

Figure 1–1
Health Is One of Many Domains of Daily Life



Source: Institute for the Future

Driven by the household context of daily life, the attention health receives waxes and wanes not only according to what is happening in the health domain itself, but also in response to the demands of all the other domains of daily life. The fate of health in the household is inextricable from the practices used to manage all the domains of daily life. Practices learned from managing finances, for example, will be applied to managing health when they are efficient, effective, or rewarding. Thus the household context of health is crucial to understand, for it shapes individuals' needs and how they will seek to meet them.

Individuals Define Health Broadly

Health and health care issues and decisions are tightly woven into the fabric of everyday life. In fact, people define "health" broadly and many of the activities of health overlap with other household activities. The health domain represented in Figure 1–2, the personal health domain, includes all of the activities individual households pursue in their quest for health and well-being. The activities people engage in regularly to support their health include exercising (going to the gym, taking a walk, dancing, stretching, swimming), diet (eating fruits and vegetables, preparing fresh food, taking vitamins), visiting the doctor (having check-ups, getting tests), sleeping and relaxing (getting a full night of sleep, taking a day off from work, meditating, doing yoga), managing health care (setting up appointments, filling prescriptions, following up with billing, paying bills) and gathering information (talking to friends, family, and providers, going online, reading books and pamphlets) These are just a few of the major areas of activity consumers pursue to support their health.

The activities in which people engage in their pursuit of health form personal health domains. Like the larger household itself, the health domain is a realm of activities that compete for time, attention, and resources. The personal health domain reflects a consumer's values, priorities and needs and is subject to the practices and patterns the consumer uses to manage his or her life.

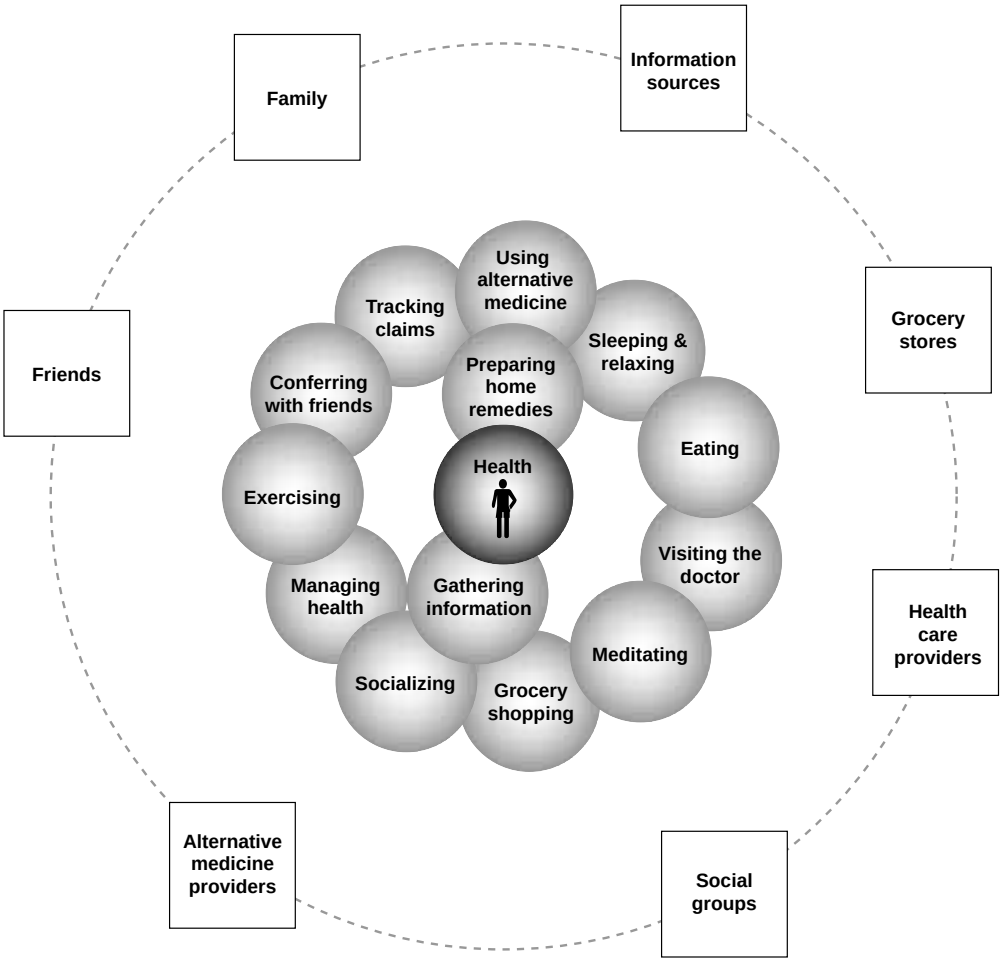
People Create Personal Systems to Manage Health

Individuals construct systems to manage their personal health domains. These systems include the resources that people deploy to manage their health domain. They may include their sources of information, their family, alternative medicine providers, expert friends, social groups, health care providers, and grocery stores, as represented in the boxes

Figure 1–2
The Personal Health Domain

Source: Institute for the Future

Figure 1–3
The Personal Health Ecology Includes Activities and Resources



Source: Institute for the Future

in Figure 1–3. The combination of the activities in the health domain and the resources individuals bring to manage them we call the personal health ecology. Each consumer constructs a distinct personal health ecology to support his or her health activities and the values inherent in those activities.

The personal health ecology is a responsive ecosystem that transforms to meet individual needs as they evolve. When someone is challenged by illness, some of the activities in the health domain and the resources in the ecology become important; for example, in the personal health ecology of someone dealing with cancer one is likely to see cancer-focused activities and resources come to the fore. The components of the ecology reflect individuals' needs as well as their ability to muster resources. The ecologies tell us something about the degree to which an individual believes that his or her health needs can be met by specific resources in the ecology. And these ecologies give insight into the value and trust people place in the resources at hand.

Personal Health Ecologies Reflect Common Needs

While personal health ecologies can show us idiosyncratic systems born out of one person's personal values and needs, there are some common desires inherent in all ecologies. Individuals seek value in health, not only in the desired clinical outcomes, but also in a variety of experiences with health products and services. They want to make informed choices, they look for credible sources of information, they seek efficiency in their interactions, they want to trust those who offer them goods and services, they want expert help, and they want to focus first and foremost on health, not the business of health. Intensity of need varies with health status and risk or level of trust. What is new here is that these common desires gain and lose salience as they compete with the demands of other household domains. Thus, viewing health behavior or health care in isolation offers only a very limited picture of how health operates in daily life. The challenge is to offer health products and services in a way that facilitates effective management of the health domain in the midst of the vicissitudes of competing household domains and demands.

The components and dynamics of personal health ecologies let us see consumers' needs and how they endeavor to fulfill them. They give us glimpses of the essential processes and the market failures that individuals are, themselves, striving to fix right now. They reveal places of opportunity for the health industry. And they do so by placing health in the organic context of broader daily life. This will be of increasing importance as individuals spend more of their own money for health care and their priorities become more prominent in health markets.

Profiles of Engaged Health Consumers

To understand personal health ecologies, we conducted a series of interviews with consumers that act as health decision makers. For all of the interviewees, we mapped their personal health ecologies. Over the next several pages in the sidebar, "Personal Health Ecologies," we present four personal health ecologies constructed from our interviews. The content and complexity of these ecologies show the intricacy of each individual's view of health as well as the common themes that drive the pursuit of health.

PERSONAL HEALTH ECOLOGIES

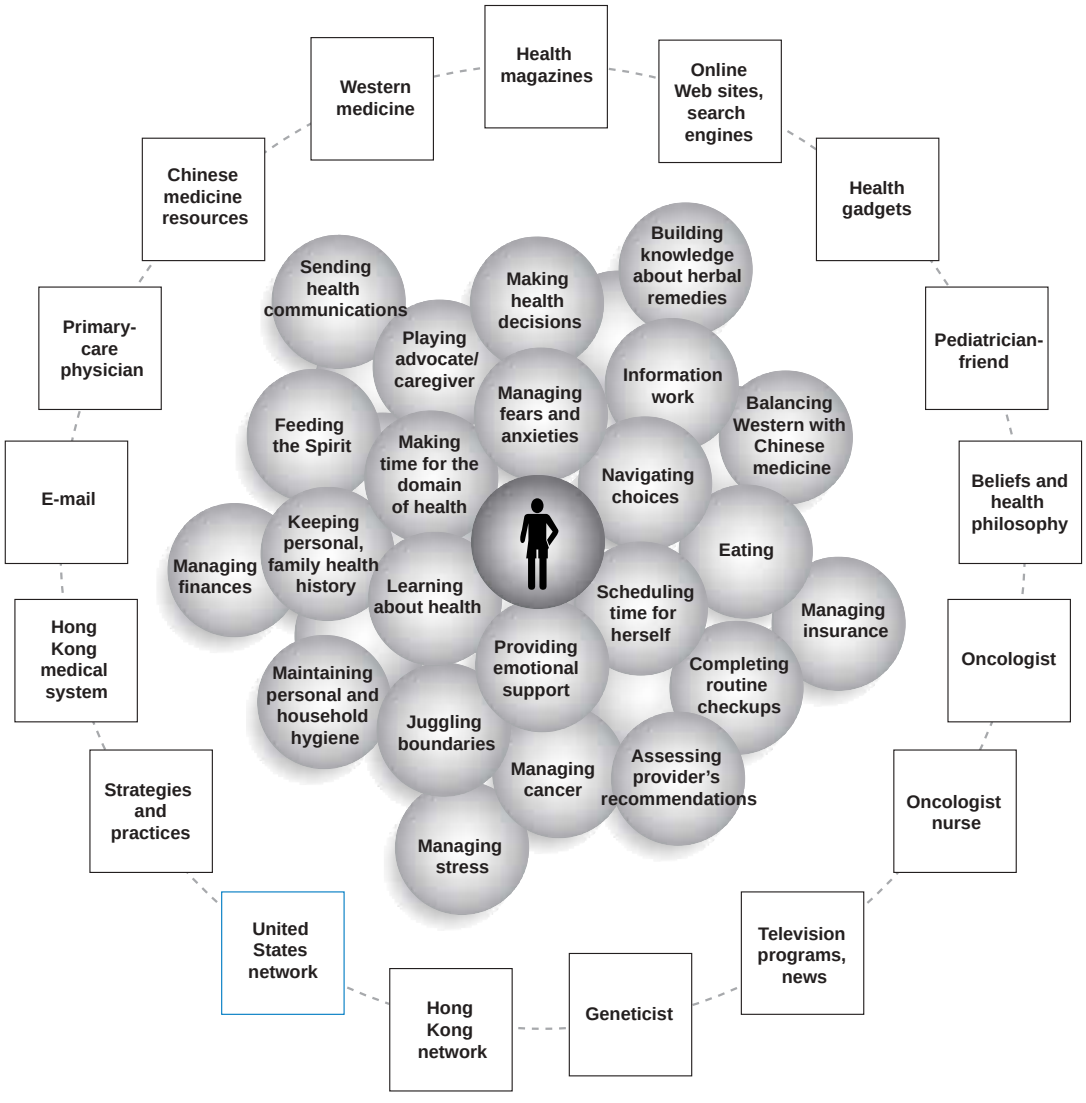
Catherine Chin:
Managing Cancer

Catherine Chin is a 48-year-old, married, working mother of two grown daughters and the health domain manager for her family. She describes herself as healthy although under a lot of stress. Both her husband and her eldest daughter have colon cancer. Her husband's cancer is in remission; her daughter is undergoing her second round of chemotherapy. Geneticists have determined that her younger daughter may also be at risk for colon cancer.

Cancer dominates Catherine's personal health ecology, and she draws upon a rich set of resources to manage it (see Figure 1–4). This ecology crosses vast geographic boundaries and extends from the San Francisco Bay Area well into her native Hong Kong. Her personal health ecology reflects her commitment to bringing the best of what Chinese and American medicine have to offer in her war against cancer. She uses technology and a diverse social network to tap into health resources and activates them as the need arises.

For resourceful, technology-savvy Catherine, managing her health ecology is a lot of work. She had high expectations of the American health system and they have not been met. She experiences the burden of navigating this unwieldy system, finding that the administrative demands it places on her are as great as or greater than the demands of caring for a daughter.

Figure 1–4
Catherine's Personal Health Ecology



Source: Institute for the Future

PERSONAL HEALTH ECOLOGIES

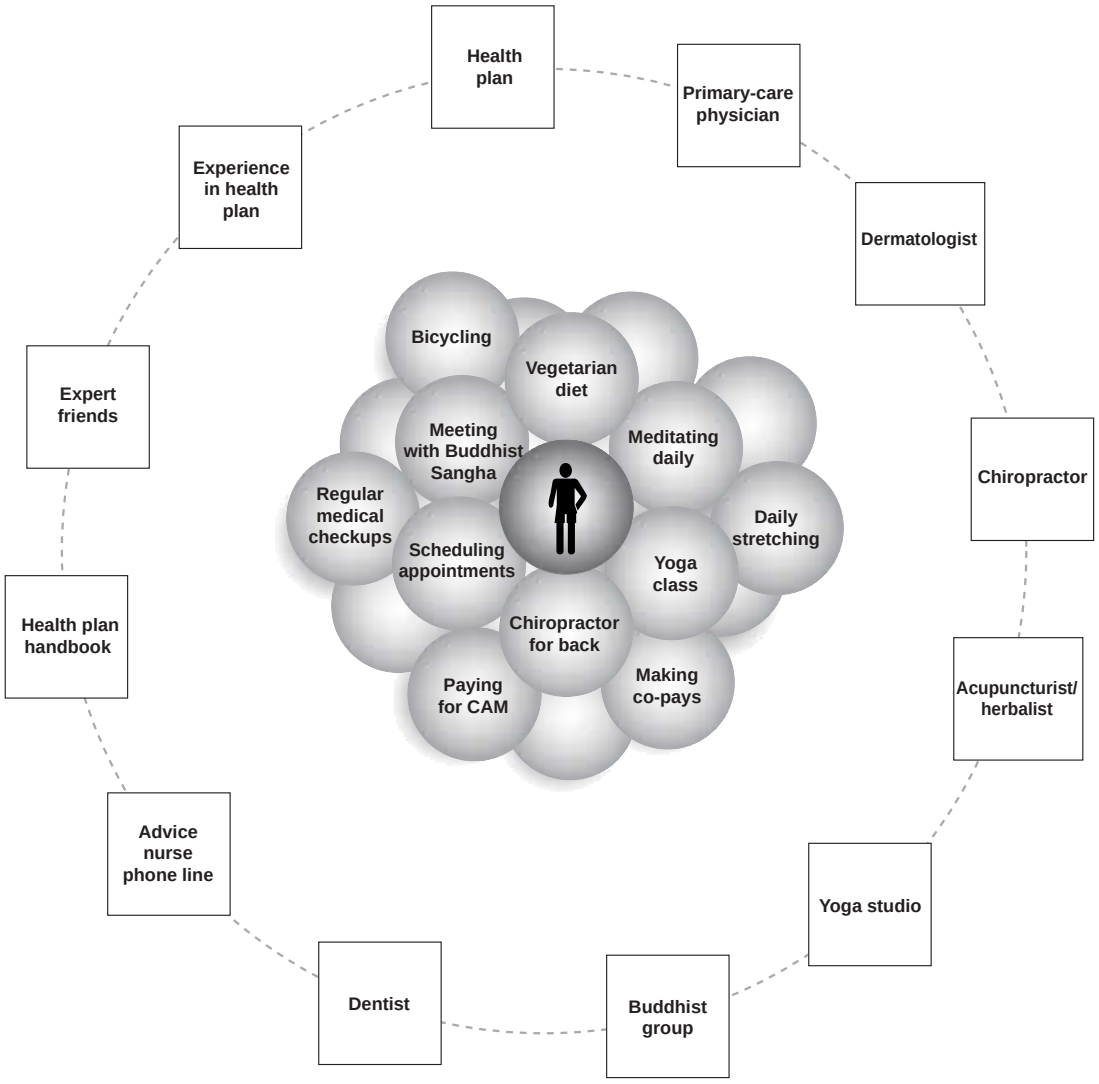
Stuart Anderson:
Integrating Alternative and Western Medicine

Stuart Anderson is a 47-year-old, married, self-employed Ph.D. with no children. He has comprehensive health insurance through his wife's employer. Stuart is healthy and takes steps to remain so. He has also reached a point in his life where he can shape his schedule to support his interests and well-being. He manages his own health and, periodically, consults with his wife for her opinions. A practicing Buddhist, he strives to ensure that the way he lives his life is consistent with his values. Those values are reflected in how he defines his health domain and the resources he integrates into his personal health ecology (see Figure 1–5).

Through his personal health ecology, Stuart draws upon complementary and alternative medicine and turns to traditional Western medicine when he believes it can serve him best. His health decisions begin with determining what things Western medicine can do well and what it cannot do well. Then he chooses providers and treatments accordingly. A regular primary care physician, a dermatologist, an acupuncturist, and a chiropractor are among his providers. In addition, meditation and exercise work together to help him achieve overall wellness.

Stuart has no hesitations about using the best resources to help him achieve health. While traditional Western medicine is covered by benefits, he expects to and readily does pay for complementary and alternative medicine out of his pocket when he believes it offers the best solutions. In his broad concept of the routes to health and well-being, allopathic approaches and yoga each have their place.

Figure 1–5
Stuart's Personal Health Ecology



Source: Institute for the Future

PERSONAL HEALTH ECOLOGIES

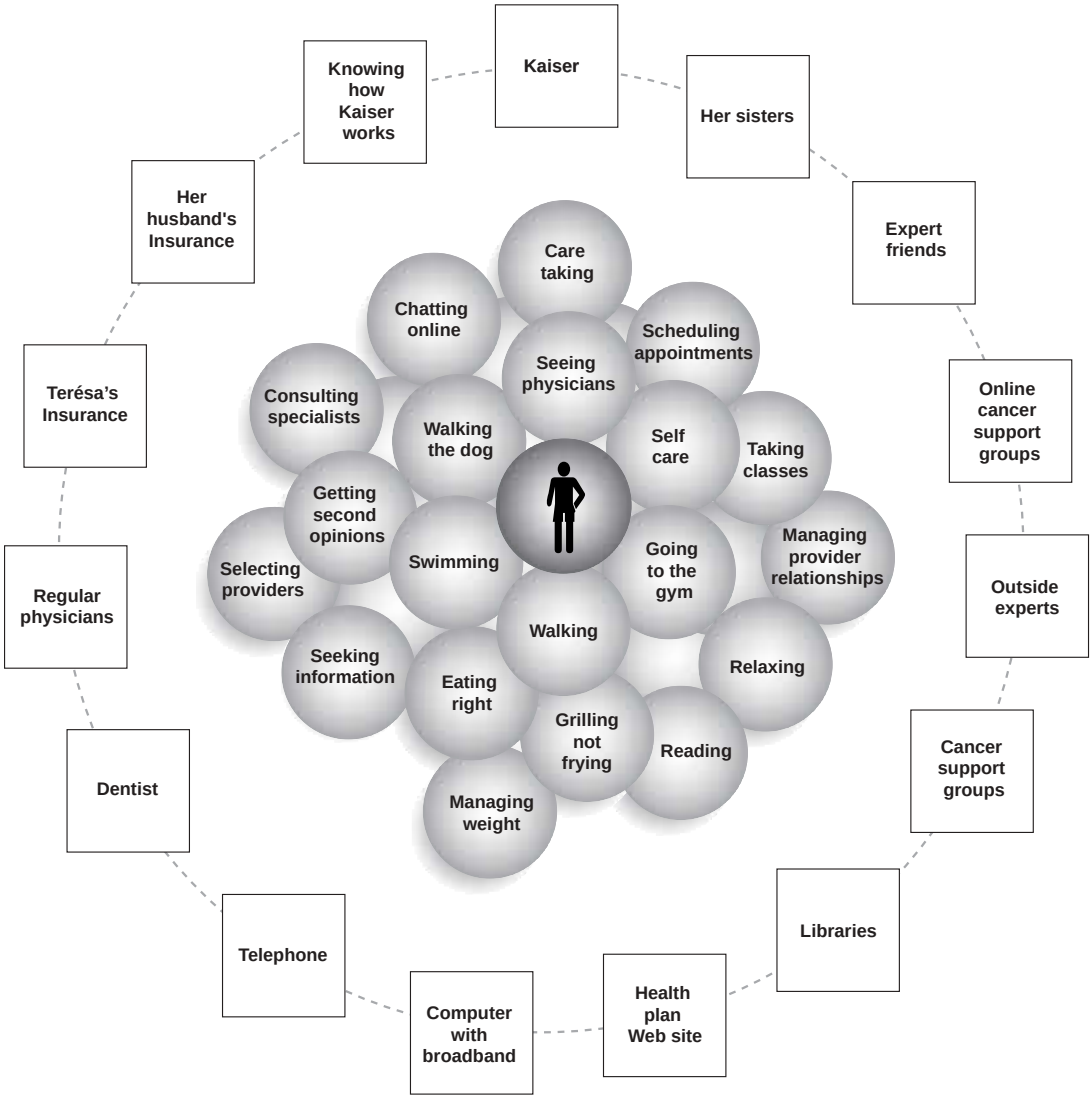
Terésa Garcia:
Maximizing the System Resources

Terésa Garcia is a 43-year-old, working mother and wife. She lives with her husband and 11-year-old daughter, and has a grown son who lives on his own but remains part of her household. Her daughter has a history of asthma and hearing loss. Her mother has undergone two rounds of breast cancer treatment. Teresa is the health domain manager, attending to health and health care issues for her household and for her mother. She is also a veteran member of a group-model HMO to which her immediate family and her mother and father belong. She is adept at capitalizing on all the resources her health plan has to offer.

Terésa has built an efficient personal health ecology (see Figure 1–6). She is heavily invested in her health plan. Having established relationships with providers and learned to navigate the system well, she can get what she needs when she wants to most of the time. She has taken great care to find providers for her daughter, maintains relationships with them, and uses their skills effectively to pursue her daughter's health.

Terésa is masterful at maximizing her health resources to help her care for her daughter and mother, and create a healthy lifestyle for her family. She has made an upfront investment in getting to know her plan and reaps the benefits of that investment. She seeks efficient service and quality health care. She gathers information first and then consults with professionals, and she advocates for what she needs. Inherent in Terésa's personal health domain is the belief that it is her responsibility to look out for herself.

Figure 1–6
Terésa's Personal Health Ecology



Source: Institute for the Future

PERSONAL HEALTH ECOLOGIES

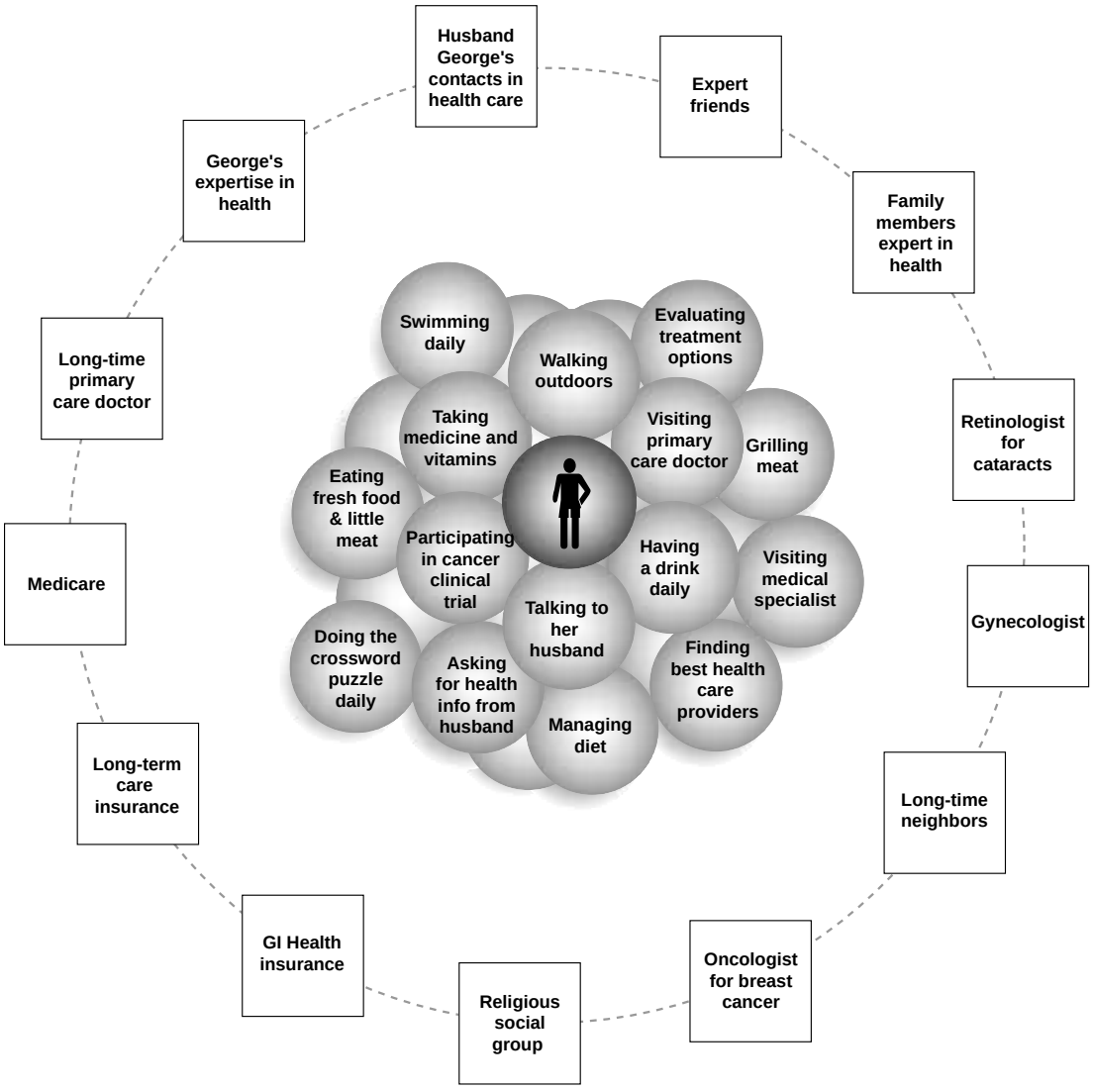
Doris Miller:
Drawing on Friends and Family to Manage Health

Doris Miller is a 72-year-old, married, mother of five grown children, three of whom live near the Washington, D.C.-area suburb she's lived in for over 30 years. She lives with her husband, George, a retired researcher and research administrator. Wired and well-connected, George gathers, filters, and helps interpret health information, and uses his extensive contacts to gain access to health care providers. Doris has survived breast cancer and a stroke and is being monitored by a retinologist for cataracts, but she is active and able to do most of what she wants to do. Doris relies on George, the household health domain expert, to advise her on health decisions including which providers to use and when to see them.

Doris' personal health ecology is full of health-promoting activities and routine maintenance within the context of long-standing relationships with physicians, all supported by her rich social network of family and friends (see Figure 1–7). While a significant proportion of it is managing health within the traditional health care system, she relies on her family and friends to simplify the information work necessary to manage health care. She is free to pursue a life that is physically and mentally active that helps her maintain her health.

Doris depends on the expertise of friends and family to ensure that she gets the best care and treatment that she can when she needs it. Her husband and grown daughter are her researchers, interpreters, and advisers. They bring her not only information but also instrumental connections that allow her to look out for her best health interests.

Figure 1–7
Doris' Personal Health Ecology



Source: Institute for the Future

Common Desires Echo in All Personal Health Ecologies

These personal health ecologies are at once startlingly different and surprisingly similar. They vary in their use of complementary and alternative medicine and traditional Western medicine. They vary in the intensity of health care needs and in the health risks they face. Yet these are all informed consumers actively engaged in the pursuit of health. Each navigates complex personal health ecologies. They all rely upon articulated social networks that are instrumental in accessing health information, goods, and services. They are all deeply immersed in the growing information work of managing health.

Inherent in these personal health ecologies is the desire for informed choice, for credible and useful information, for trusting provider relationships, for efficiency in their administrative interactions in the health care system, for expert help, and for the ability to focus on health not logistics.

Chapter 2

Engaged Health Consumers and Health Decisions

Consumers engaged in health are those individuals who are active in their health and health care and act consciously to further their own health interests or those of their loved ones. The concept of "engagement" is intended to capture behavior—an important factor for understanding the evolution of consumers in health and health care. What's more, when it comes to health, behavior is critical as health behaviors account for 50 percent of morbidity.[1]

The Health Engagement Index

To gain greater insight into those individual consumers who are most actively engaged in their own health and wellness, we have quantitatively measured health consumer engagement with what we call the "Health Engagement Index." The behaviors in our index were chosen to reflect the hallmarks of the engaged health consumer—the desire for multiple perspectives on important health questions, engaging in regular and frequent activities to optimize health, and identification as a health decision maker in the household.

To create our index, we used data from IFTF's 2002 Household Survey of 1,500 Americans. Specifically, we asked respondents whether they have any responsibility for managing their household's health and health care, how much time they spend on average managing their household's health and health care, whether they have looked for information about alternative medical treatments in the last year, whether they made a change to their diets in the last year to be healthier, and whether they take nutritional supplements daily (see Table 2–1 on page 24).

We focused on consumers who make and implement decisions regarding their families' health. In our survey, 85% of respondents claimed to have most or all of the responsibility for managing their households' health and health care. (Individuals who reported that they lived alone were defined as having most or all of the health responsibility.)

We assumed that individuals who don't identify themselves as health decision makers are, for whatever reason, unable to act upon their health preferences, and so defined them as "low engagement." Of the remaining 85%, we assigned a "point" to respondents if they were in the upper one-half or one-third (depending on the question) of the distributions for the other health questions. The total number of points an individual accrued determined their rank on the index, from low (0 points), to medium (1–2 points) or high (3 or more points). For example, if a person reported having most of the responsibility for managing their households' health and health care and reported taking nutritional supplements daily, but did not report any of the other behaviors listed in Table 2–1, they would be characterized as having medium health engagement level (one point) on our scale.

WHO ARE ENGAGED HEALTH CONSUMERS?

Engaged health consumers, those individuals who act consciously to further their own health and health care interests, form a significant portion of the population. In fact, one third of all consumers are highly engaged health consumers (see Figure 2–1.)

More Education Means Higher Engagement

Engaged health consumers have higher education levels. Consumers with high health engagement are almost twice as likely as low engagement consumers to be college graduates (see Figure 2–2). Engaged health consumers tend to have more education, a characteristic that helps them synthesize health information from multiple sources. However, those with less education can still be engaged in their health—more than one quarter (28 percent) of engaged health consumers have a high school

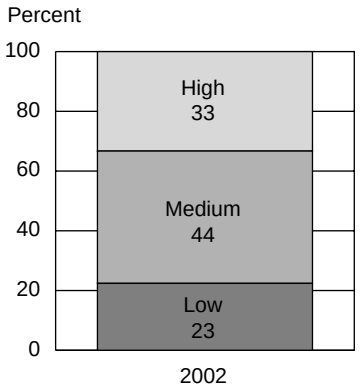
Table 2–1
The Health Engagement Index Components
(Percent of U.S. population)

Characteristic	***Percent***
Has some, most or all responsibility for managing household's health and health care*	82
Spends at least one hour per week managing their household's health and health care	74
Made diet change within the last year to be healthier	69
Looked for information about alternative medical treatments in the last year	56
Takes nutritional supplements daily	54

* Individuals who reported that they lived alone were defined as having most or all responsibility for managing their household's health and healthcare.

Source: Institute for the Future, Household Survey 2002.

Figure 2–1
Consumers Display a Range of Health Engagement
(Percent of the U.S. population health engagement level)



Source: Institute for the Future, Household Survey 2002.

education, and another 10 percent have completed even less schooling. This is not surprising since engaged consumers often have people and other resources in their personal health ecologies that help process and make sense of health information for decision making.

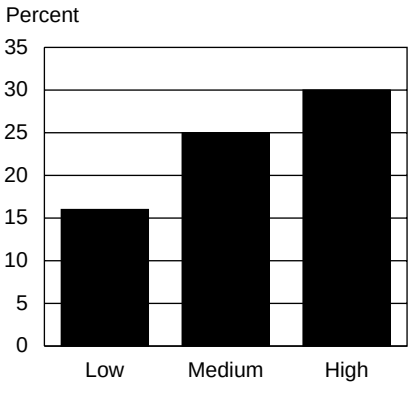
More Income Does Not Necessarily Mean Higher Engagement

Engaged health consumers appear in all income strata. Roughly one-third of each income category qualify as engaged health consumers—about the same share as the overall population (see Figure 2–3). The most likely triggers for high health engagement—life-stage transitions and the incidence of illness—impact people in all income groups. Therefore it is not surprising that increasing income is not strongly related to increased health engagement. While higher income does open more options and health resources for some, we found that health status or being in the middle of a life-stage transition, such as becoming a parent or caring for a chronically ill parent, was a much more important determining factor of health engagement than income alone.

Highly Engaged Tend to Be Women

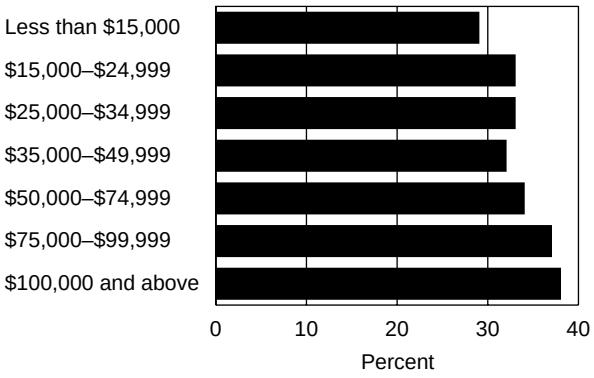
Not surprisingly, women are more likely to be engaged health consumers. Over 60 percent of highly engaged health consumers are women (see Figure 2–4 on Page 26). Numerous studies have shown women to be the dominant health decision makers for their households. The Commonwealth Fund reported that 79 percent of women with children choose their children's doctor, 84 percent of them accompany children to the doctor, and two-thirds of women select their family's health plan. Most (53 percent) are the sole household health decision maker, with a small minority making decisions with their spouse (12 percent).[2]

Figure 2–2
Engaged Health Consumers Are Highly Educated
(Percent of respondents who have at least college degree, by health engagement level)



Source: Institute for the Future, Household Survey, 2002.

Figure 2–3
Engaged Health Consumers Span Income Categories
(Percent of highly engaged health consumers, by income level)



Source: Institute for the Future, Household Survey, 2002.

Engagement Highest in the Middle Years

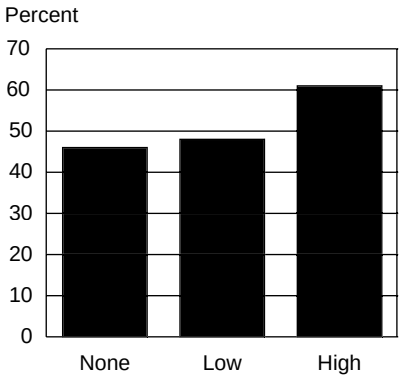
Overall, the age distribution of engaged health consumers reflects each age cohorts' health status and formative experience with health and health care, rather than age alone. We anticipated that the older individuals get, the more health issues they have, and the more engaged they would be. But in fact, those 65 years of age and older are a smaller proportion of highly engaged consumers than are each of the three younger age cohorts (see Figure 2–5). This surprising result is likely to be related to this age group's long-term experience with health care.

For the most part, members of the senior cohort have been covered by indemnity insurance for most of their lives and have allowed their doctors to play the most important role in making their health care decisions. In contrast, those born in the late 1950s and later interacted with the health care system during an era of managed care that eroded physician authority. Still, the influence of age on health needs, and engagement, is not absent. There are fewer highly engaged consumers between the ages of 18 and 24 simply because few of these individuals have encountered age-related health problems. Higher levels of health engagement exist among baby boomers, who have more experience with the health care system, seek out more information, and take a more active role in health decisions. As these people move into their senior years toward the end of the decade, the engagement of those 65 and older is likely to increase.

Engaged Look for More Health Information

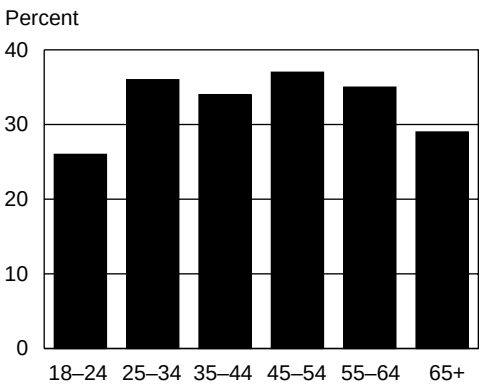
Engaged health consumers look for health information from more sources and are intensive users of information for health and health care decision making (see Figure 2–6). In fact, highly engaged health consumers are more likely than other health consumers to use four or more sources of information when looking for health information. This intense use of

Figure 2–4
The Most Engaged Health Consumers Are Women
(Women as a percentage of each level of health engagement)



Source: Institute for the Future, Household Survey, 2002.

Figure 2–5
Health Engagement Peaks in Middle Age
(Percent of highly engaged health consumers, by age)



Source: Institute for the Future, Household Survey, 2002.

information and range of resources used is often reflected in the complexity of engaged health consumers' personal health ecologies.

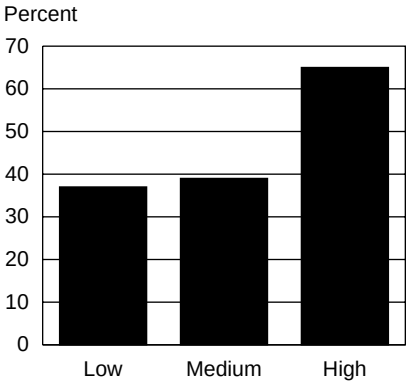
Engaged health consumers can have influence on their friends, family, and strangers when it comes to health matters. Engaged consumers not only search for information, they disseminate it, too, in their role as "chatters." Chatters hear about new things first, and then they tell others about it. Over 26 percent of highly engaged health consumers in our 2002 survey view themselves as chatters, compared with 17 percent of those who are not engaged. These consumers are most likely sharing their ideas with friends and family, but highly engaged consumers can have impact in the wider world as well.

Planetfeedback, an organization that tracks and facilitates online consumer feedback about products and services, has ranked health care as one of the most "viral" industries. Virality is defined as the degree to which consumers write about companies, products, and services, and share what they write with others.[6] The implication here is that Web sites like Planetfeedback.com provide a tool for highly engaged health consumers to share their ideas and opinions with others beyond their immediate circle of friends and family.

More Likely to Act on Health Information

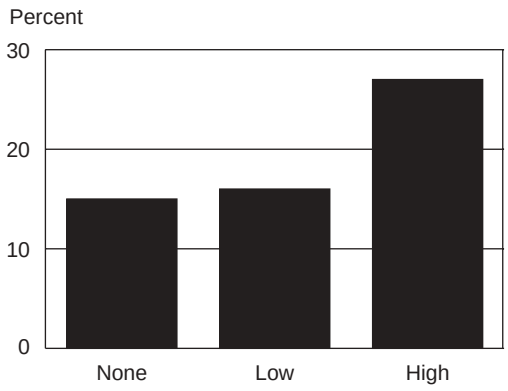
Engaged health consumers are almost twice as likely as those in other health engagement categories to go online several times a day (see Figure 2–7). The Pew Internet and American Life Project found that individuals who go online frequently are more likely to act on health information they receive. In their 2002 survey, 44 percent reported that such information affected their decision about how to treat an illness, 38 percent claimed that it led them to ask a doctor new questions or to get a second opinion, and 34 percent said it led them to change their approach to maintaining their own health or that of someone in their care.[4] Similarly, in a 2002 survey CyberAtlas found that

Figure 2–6
Engaged Consumers Look for Health Information from More Sources
(Percent of respondents that looked for health information from four or more sources, by health engagement level)



Source: Institute for the Future, Household Survey, 2002.

Figure 2–7
Engaged Consumers Are Intensive Users of the Internet
(Percent of respondents that go online several times a day, by health engagement level)



Source: Institute for the Future, Household Survey, 2002.

frequent Internet users are more than twice as likely to take actions that will affect their health care. Thirty-six percent use the information to self-diagnose and suggest diagnoses to their clinicians. Forty-five percent actually ask for specific treatments.[5] Engaged consumers come to health markets and providers armed with information and an agenda.

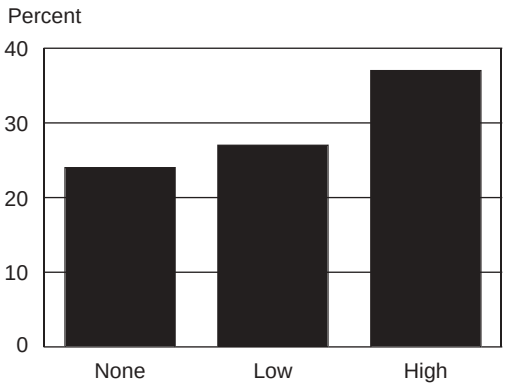
Chronic Illnesses Increase Engagement

Engaged consumers are more likely to have a chronic illness (see Figure 2–8). This finding is consistent with our interviews that found that persons with chronic illness were highly engaged in their own health and health care. Our interviews also illustrate how a seminal health event, such as a new diagnosis, transforms consumer behavior, prompts increased health engagement, and activates resources in a person's personal health ecology. For a 43-year-old man, the diagnosis of serious, chronic disease was an event that changed his relationship with the health care system:

> It becomes a matter of self-preservation. I need to find out more so I know that the treatment I'm getting is the best treatment that I can receive. … I'll tell you right now, if I didn't have the health issue with things going on, I would never have done what I do. But when it hits you, you don't have any alternative. It becomes a time when you need to become more informed and you start to question what the authority is telling you.

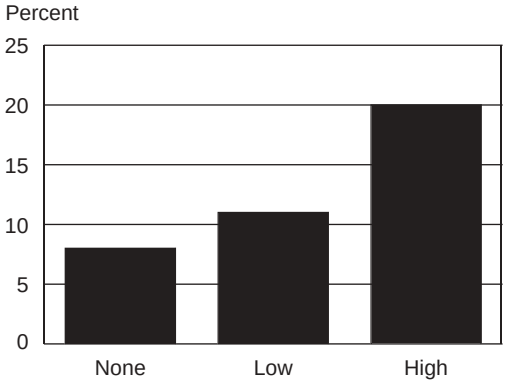
Engaged health consumers are more likely to be responsible for those with chronic illness than are less engaged consumers (see Figure 2–9). That responsibility makes them advocates for those in their care. One of the working

Figure 2–8
Engaged Health Consumers Are More Likely to Be Chronically Ill
(Percent of respondents with chronic illness, by health engagement level)



Source: Institute for the Future, Household Survey, 2002.

Figure 2–9
Engaged Consumers Are Responsible for Others with Chronic Illness
(Percent that cares for chronically ill person, by health engagement level)



Source: Institute for the Future, Household Survey, 2002.

mothers we interviewed cares for both a daughter and mother with health problems and told us flatly that:

> If you've got something wrong, you push it until they ... say they will look at it. I really feel that the ones who do the pushing are the ones who are going to get the better treatments. I did learn that. That was not a really good learning experience but it was an experience that I will remember forever.

Spend More Out of Pocket

Engaged health consumers are likely to spend more money out of pocket for health expenses (see Figure 2–10). The combination of higher out-of-pocket spending and high health engagement points to a group of consumers that go outside of the traditional health care system to get their health needs met.

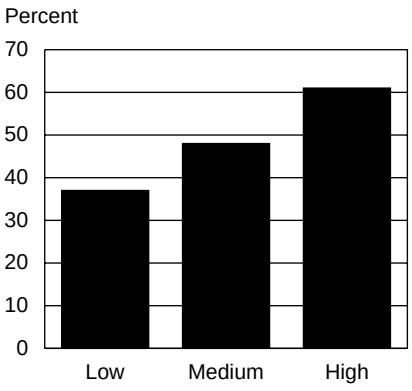
Have Health Management Technologies in the Home

Highly engaged health consumers are more likely to own a device to monitor or provide a health treatment (see Figure 2–11). This is not surprising as new technologies and devices are increasingly finding a place in the home for health management and other wellness activities.

How Engaged Health Consumers Make Decisions

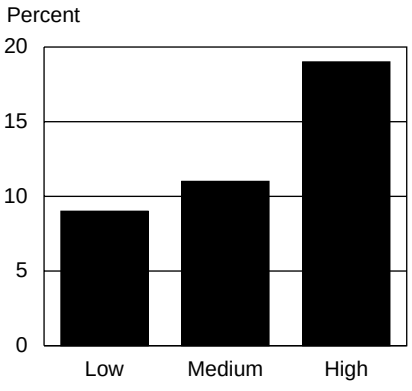
Individual consumers exhibit health engagement in the marketplace of health goods and services, from selecting health insurance and assessing medical treatments, to choosing a physician, finding an acupuncturist, and buying vitamin supplements. Each decision however small or big—from an engaged health consumer's point of view—involves a careful assessment of risk and trust. The health decisions and the process of decision making among engaged health consumers can be quite complex.

Figure 2–10
Engaged Consumers Pay More Out of Pocket for Health Expenses
(Percent of respondents that paid $500 or more for health expenses in 2001, by health engagement level)



Source: Institute for the Future, Household Survey, 2002.

Figure 2–11
Engaged Consumers Are More Likely to Own Health Management Technology
(Percent of respondents whose household owns a device to monitor health or provide a health treatment, by health engagement level)



Source: Institute for the Future, Household Survey, 2002.

Because of the potential impact or risk of certain health decisions and the sheer complexity of many of them (e.g., diagnosis, symptoms, treatments, providers, self-care and alternative options, insurance coverage and benefits), they are often distinct from other decisions and processes of decision making in daily life. Deciding what kind of provider and treatment will help alleviate back pain might involve deciding whether to see a physician or a massage therapist, take a drug, or enroll in a yoga class. This decision process is very different from deciding which carrier to select for mobile phone service. How an engaged health consumer asserts herself in any specific health decision depends largely on the interplay of two factors: the risk she faces (e.g., health or financial) and the trust she places in the resources at her disposal.

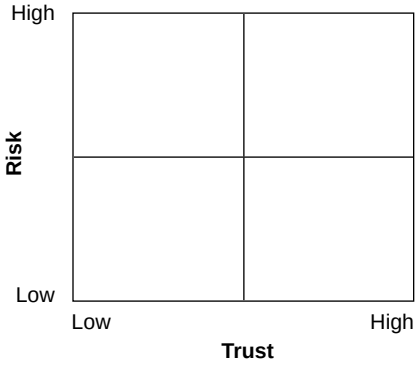
The Interplay of Risk and Trust

The level of personal risk involved in specific health and health care decisions and the trust one places in the resources at hand shape decision making. Figure 2–12 offers a framework for thinking about how engaged health consumers navigate health decisions. Personal risk, for example, is much higher in the context of serious or life-threatening illness like cancer or health-related events like pregnancy. Trust also shapes health decision making. For a newly diagnosed cancer patient, for example, trust in information sources and providers can reduce the sense of risk in decision making. On the other hand, the lack of trust or access to trusted information about treatments increases the sense of risk of decisions in that context

Both dimensions—risk and trust—interact in a range of health decisions (see Figure 2–13). The higher the risk and the lower the trust in health care providers, the more consumers rely on their social networks or on information sources outside of the health care system to make decisions. What's more, they are more likely to retain control of their decision making and seek out second and third opinions rather than accepting one provider's diagnosis or recommendations. Such high-risk, low-trust decisions are distinct from other kinds of household decisions. For decisions where the trust is high and the risk is low, health consumers spend less time and energy in decision making; efficiency, cost, and convenience become more important. As a result, such health decisions begin to look similar to other low-risk household decisions.

There are two situations in which health decisions may be relatively simple: when risk is low and trust is high and when risk is low and trust is low. Since the possibility of serious outcome is not great, even engaged health consumers may invest little time or energy to gather information and make decisions. Examples of these kinds of decisions from other household domains are decisions about relatively inexpensive household items or low-risk financial investments. What consumers want is efficiency, ready access to goods and services—including relevant information—and convenience. Good customer service and efficient administrative processes will meet

Figure 2–12
Health Decisions Are Shaped by Risk and Trust



Source: Institute for the Future

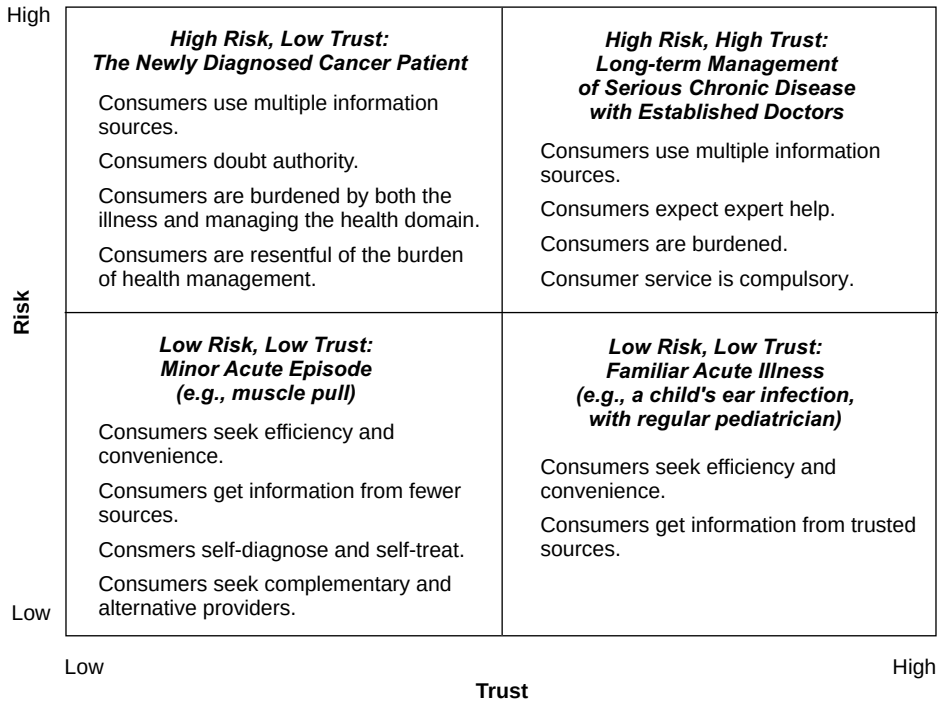
their needs. For example, take the view of a 47-year-old man:

> I often have questions that are not acute questions. You know, why should I wait on the phone line talking to an advice nurse when I can send an e-mail and get a response within a day, two days, or a week? That would be fine for me sometimes.

When risk is high, however, engaged health consumers will employ a more complex decision-making process. If personal risk is high and trust is low, engaged consumers will gather information from multiple sources before making a decision. Not only are they seeking information and verifying it, but they are also trying to get a glimpse of the experience of having a particular illness, treatment or working with a specific provider. Engaged health consumers use both analytic and intuitive modes of decision making. By gathering information and tapping their social networks they try to bring both to their aid in making health decisions.2 This practice of bringing information and social capital to bear on health decisions is key to the concept of health engagement.

When risk is high and trust is high, engaged consumers are likely to expect expert advice from their own health care providers and look to them as trusted sources of information. In fact, health care providers often are used by engaged consumers as resources both for wading through information sources and for understanding the experiences that are likely to result from their decisions. For example, one

Figure 2–13
The Interplay of Risk and Trust Creates a Whole Range of Health Decisions



Source: Institute for the Future

woman who was working with her sisters to care for her mother when she had a recurrence of breast cancer reported:

> We went to four or five doctors. … We went to the libraries, we went to the Internet, we went to friends who had gone through it before, we went to [a hospital that] has this really big cancer research program over there and we picked up a lot of information from them.

This woman and her family also spoke with cancer patients themselves. She did this even though she trusted the health system she and her mother belonged to, a system she was skilled in using. The implication for companies that provide health goods and services is that decisions made when the risk is high are extremely burdensome to even the most engaged consumer. Such decisions may take more rounds of input and providers may need to accommodate the engaged consumer and his or her advisors in the service decision. These competent health care consumers want respectful, expert consultation so that they can make informed decisions with their providers.

Although risk and trust interact to help shape decisions of all kinds, they are particularly potent in health and health care. This is simply because high-risk decisions happen more often in the complex and, often emotionally charged, situations that arise in health and health care. So while health and health care providers must develop the good customer service, efficiency, and convenience required for all consumer-based decisions, they must also accommodate complex decisions with multiple participants and multiple sources of diverse information to support high-risk decisions. And they must participate in joint decision making with engaged consumers. This consultative decision making requires providers to respect engaged consumers' competence while at the same time offering credible expert help and assisting them in grasping the effective impact of high-risk health decisions.

Defining Value for Engaged Health Consumers

Staking out a role in people's health ecologies—becoming a resource or a tool people use to manage health or health care in their daily lives—is one of the best ways to provide value to health consumers. Engaged health consumers rely on a whole range of products and services, practices, and relationships to manage their health and personal health ecologies. Engaged health consumers rely on practices common in their daily lives and make decisions based on their values and their needs. Resources in consumers' personal health ecologies will extend far beyond the traditional infrastructure for medical care to grocery stores and gyms, alternative medical providers, and social groups.

Underlying engaged health consumer values is the earnest desire to focus on health—the broad definition of health that includes physical and mental well-being. Consumers, engaged health consumers in particular, wish to live healthy lives. Thus they focus on health itself rather than the mechanics of health care and they look to their providers to support this focus. Finding ways to facilitate this in people's everyday lives will create significant value and loyalty.

Endnotes

[1] Institute for the Future. *Health and Health Care 2010, The Forecast The Challenge*. San Francisco, CA: Jossey-Bass, 2000.

[2] Hibbard, J., and Peters, E. Supporting Informed Consumer Health Care Decisions: Data Presentation Approaches that Facilitate the Use of Information Choice. *Annual Review Public Health* 2003; 24,7:1–21.

[3] Scott Collins, K., et. al. *Health Concerns Across a Woman's Lifespan: The Commonwealth Fund 1998 Survey of Women's Health Decisions*. New York, NY: The Commonwealth Fund, 1999. www.cmwf.org.

[4] Fox, S., and Rainie, L. Vital Decisions, How Internet Users Decide What Information to Trust When They or Their Loved Ones Are Sick. Pew Internet & American Life Project, 2002. www.pewinternet.org.

[5] Pastore, M. Online Health Consumers More Proactive About Health Care. CyberAtlas, 2002. http://cyberatlas.internet.com/markets/healthcare/article/0,,10101_755471,00.html.

[6] Planetfeedback, 2002. www.planetfeedback.com.

Chapter 3

Drivers and Barriers for Health Consumer Engagement

Health care industry players and consumers stand at a sea wall watching a rising tide of health care costs. The question is: Will that tide be forceful enough to bring in the value-based consumerism that health care consumerists advocate? Will industry moves actually put consumers—individual health care users—in the driver's seat?[1] Will consumers be engaged and not only make price-conscious choices about the services they receive, but also advocate for their own needs? In this chapter we look at both drivers that are likely to increase consumer engagment, and the barriers that will slow or stop the trend toward engagement.

Drivers of Rising Consumer Engagement

There are two sets of drivers will promote consumer engagement in health and health care decision-making. Pressure will come from both the realities of consumers' daily lives and the strains on the health care industry and its primary customers, businesses.

Consumers Driven to Engagement

Four factors will drive consumers to engage more intensively in health and health care over the next ten years:

- Increased out-of-pocket spending.
- Increased attention to health issues because of the affects of aging.
- Lack of trust in health care.
- Increasing access to health information.

Taken together, these forces will have the effect of increasing consumers' stake in the value of the health goods and services they receive.

Cost Is Not Just a Purchaser Issue

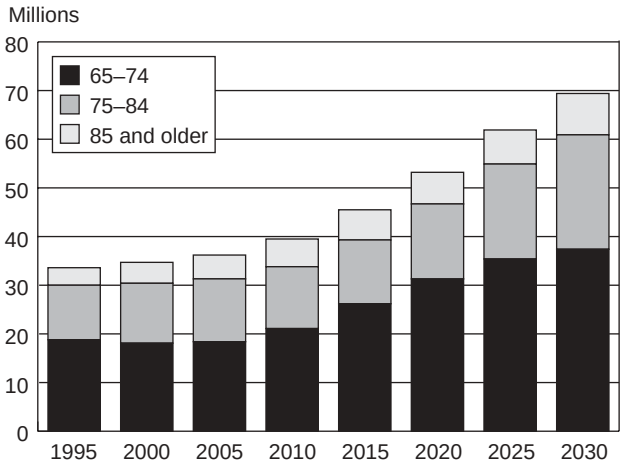
History tells us that when consumer health care costs rise, consumers take steps to save money. Those who can, find less expensive options by choosing slimmer benefits for example. Others delay care, or decline insurance altogether. In their 2001 consumer survey, Kaiser Family Foundation and Harvard School of Public Health found that 22 percent of respondents had postponed care. Of these, 43 percent could not afford the uncovered portion of their health care—co-pays, co-insurance, and deductibles.[2] That number is growing and is reaching into the ranks of the middle class. Future cost increases will drive more consumers to take notice and shift their own behavior both in selecting insurance and in using health services.

Demand for Health Care Increases with Age

The American population is aging and with age comes increased demand for health goods and services. By 2010 nearly 40 million Americans will be 65 and over (see Figure 3–1). The prevalence of chronic conditions mounts with age. Sixty-two percent of those 45 to 64 cope with one or more chronic conditions and 84 percent of those 65 to 74.[3] Health expenditures increase with age too. Annual per capita health expenditures for those over 65 are nearly three-and-a-half times the spending for those under 65.[4] And spending on prescription drugs by seniors is expected to increase significantly (see Figure 3–2).

As aging boosts consumer demand for health goods and services, the marketplace will provide a growing menu of options. That menu ranges from boutique medicine and stand-alone, direct-to-consumer diagnostics to complementary medicine, organic foods, primary providers, and personal trainers. Already 68 percent of Americans have used at least one form of complementary and alternative medicine (CAM). The prevalence of CAM use increases with each generation. While five out of ten baby boomers use CAM, seven out

Figure 3–1
The Coming Surge in the Population Over 65
(Population 65 and older in the United States)



Source: Institute for the Future; U.S. Census Bureau.

of ten members of the post-baby boom generation do.[5] As these cohorts age, the array of health goods and services they will seek, use, and pay for will grow as will their role as true health consumers.

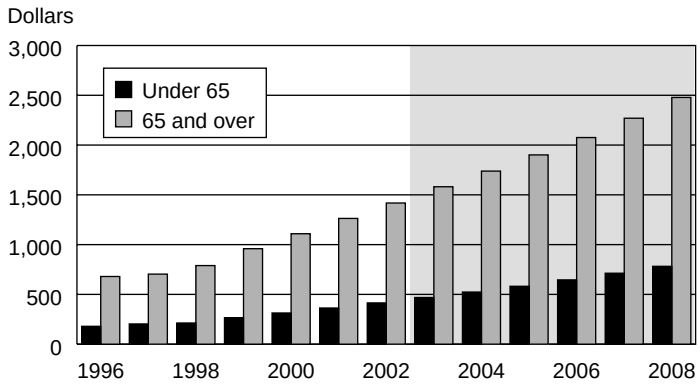
Consumer Trust in Health Care Is Shaky

One of the by-products of the managed care backlash has been lack of confidence in the traditional health care system. While the majority of consumers believe that doctors (75%), nurses (89%), and hospitals (67%) do a good job, the same cannot be said for HMOs, health insurance companies, and managed care companies. They rank second, third, and fourth respectively, behind oil companies when it comes to those that Americans say they are doing a bad job.[6]

Consumers also worry about whether their best interests are being served. Sixty-two percent of Americans worry that their health plan would be more worried about saving money than about what is best for their health. Fifty-three percent worry that the quality of health care services will get worse.[7] The Center for Studying Health System Change found that just under 45 percent of privately insured Americans believed that their doctors are strongly influenced by their health plans. And even though the vast majority (93%) trust their doctors to put their needs first, people who have the most contact with doctors, those in fair to poor health, trust doctors less.[8]

These worries prompt consumers, particularly those who really need health care, to look out for their own best interests. They do so by relying on experts in their own social networks or tapping into the experience of fellow consumers. Planetfeedback, for example, capitalizes upon the trust that consumers place in fellow consumers through consumer-to-consumer communication channels.[9]

Figure 3–2
Prescription Spending by Seniors Will Increase Sharply
(Annual per capita prescription drug spending)



Source: Medical Expenditures Panel Survey, 2002.

Access to Information Arms Health Consumers

The Internet and the plethora of health coverage in the media have given consumers unprecedented access to health information. Many savvy consumers search for information first and go heavily armed with data when they visit providers, be they primary care physicians or acupuncturists. The most sophisticated consumers are aware of allopathic as well as CAM treatment options and may know something of other patients' treatment experiences. Direct-to-consumer advertising of everything from prescription drugs to full-body scans is another source of information—one that usually increases consumers' demand for health care services.

Consumers gather all this information because they suspect that the system does not look out for their best interests and that information is their best defense. Whether it is sought by consumers or foisted upon them, information makes consumers aware of a bigger menu of health choices. However, it also complicates their decisions, putting the onus on them to filter and evaluate what they hear. Many of them need and will seek help in performing that task. (For more, see "Information, New Options, and New Pressures in Daily Life.")

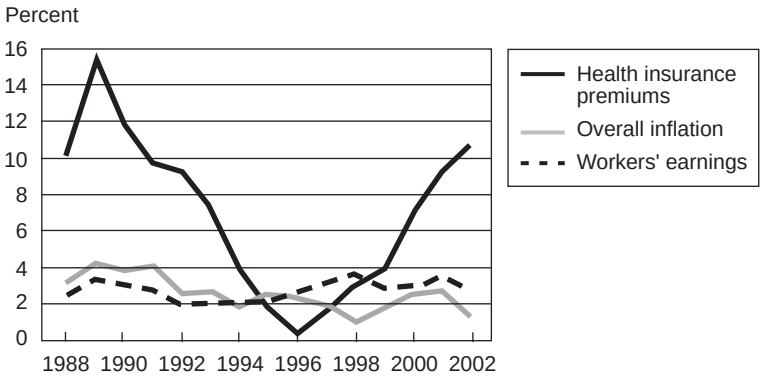
Health Industry Looks to Consumers

Health care purchasers and plans will exert new efforts to control rising health expenditures by shifting costs to consumers and experimenting with the new consumer-directed benefits models that they believe will help them.

Purchasers Are Shifting Costs to Consumers

Employers simply cannot keep up with health care costs and they are looking for solutions to help rein in costs. The divergence between premium growth and that of the overall economy is staggering (see Figure 3–3). Health premiums grew at 10.6 times the rate of GDP growth in 2002. In the same year, Hewitt Associates reported that the employers it surveyed anticipated a 5-percent gap between the projected growth rate in health care costs and the average maximum amount they have

Figure 3–3
Employer Health Insurance Premiums Continue to Soar
(Average annual percent growth)



Source: Gabel, Levitt, Holve, et al., *Health Affairs*, Vol. 21, No. 5, 2002.

INFORMATION, NEW OPTIONS, AND NEW PRESSURES IN DAILY LIFE

Information technologies in general, and the Internet in particular, have transformed daily life. In 2002, The Pew Internet & American Life Project estimated that on an average day 64 million people go online in the United States. They e-mail, bank, gather information, and make transactions. Increasingly, Americans are using the Internet for substantive and functional communications such as seeking advice and discussing issues that trouble them.[10] In 2002, 73 million Americans, or 62 percent of Internet users, used the Internet to gather health information.[11] The number of Americans with broadband Internet connections at home has quadrupled since 2000, altering the nature, amount, and frequency with which they gather information, create content, and disseminate information. Of course, wireless networks make connection ubiquitous. While this may allow individuals to make more informed decisions, it has the potential to dramatically increase the workload for managing the domains of their daily lives.

Changes in health and health care are occurring in the midst of this information deluge, but more information is not necessarily better in health. Many of the most serious health decisions are made in situations that are both complex and unfamiliar.[12] They may also occur in the context of fear, pain, doubt, or unfounded optimism. While people do use information in making health decisions, the torrent of information available electronically may add to the burden of decision making. People will need help sorting through this information before making decisions.

There is a tension between the increasing demands of daily life and the desire to increase individual participation and responsibility in health and health care. Not only does the health domain complete with other domains, but health is complex and often emotionally charged. Those who compete in health markets will have to simplify and tailor information to capture consumer attention and reduce the frustrations of health and health care users who are striving to manage over-burdened households.

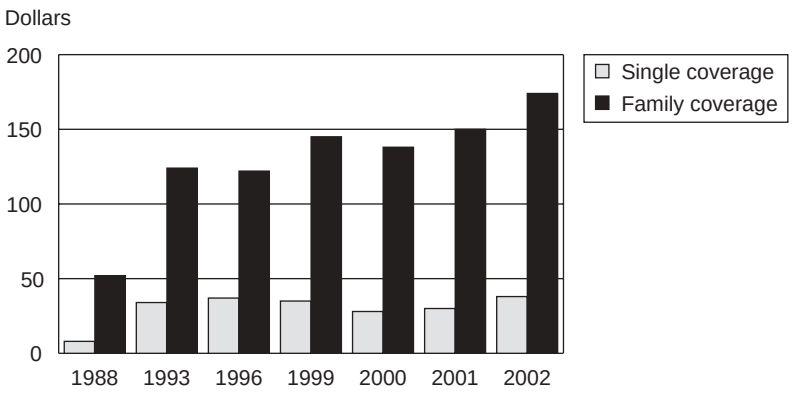
budgeted and can fund for health care over the next five years.[13]

In the face of the gaps between projected expenses and available funds, and between overall economic growth and health cost growth, employers are shifting costs to consumers. Employees saw a 27 percent increase in their nominal contributions to premiums for themselves and a 16 percent increase for their dependents in 2002 (see Figure 3–4). They also paid more out of pocket for co-pays and deductibles, particularly if they chose to get services outside of their plans.[14] Despite these increases, employers' share of health care cost has remained constant, leaving room for greater cost shifting in the face of accelerated premium growth and sluggish economic recovery.

Consumer-Directed Plans Offer Hope

Purchasers are also experimenting with consumer-directed models of care. These models vary in structure, but they share the goal of creating incentives that engage employees in making active choices about their benefits and conscious trade-offs between the kind of services they receive and the prices they pay. While not drivers of the shift toward greater health consumer engagement themselves, they create a vehicle through which consumer engagement can be exercised and bank on the fact that consumers will, indeed, take charge of their own health and health care. These plans are clearly in their infancy: of the roughly 174 million Americans covered by private health insurance only about 1.5 million people are enrolled in these plans. Some of them are only two years old. And big plans are just introducing consumer-directed offerings. Should they prove to save money and be acceptable to consumers, they may grow as a segment of the private insurance market. Some forecast that they could reach 15 to 20 percent of the insurance market in the next several years.[15]

Figure 3–4
Consumers Are Paying More for Health Insurance
(Average monthly consumer contribution to premiums for employer-sponsored health insurance)



Source: Institute for the Future; Kaiser Family Foundation, *Health Research and Educational Trust Survey of Employer-Sponsored Health Benefits*, 2002.

Barriers to Increasing Consumer Engagement

The barriers to consumer engagement in health markets are formidable and will make the change evolutionary rather than revolutionary. We forecast that an increase in consumer engagement will occur, but that it will take from 15 to 20 years to reach fruition—if it is not reversed. There are several barriers that will set the pace of change inherent in this forecast:

- There may be a consumer backlash to having too many or overwhelming new responsibilities for health and health care.
- The complexity of health and health care markets obfuscates rational consumer decision making.
- Businesses may be unable to bring about the culture change required to deliver consumer-centered services that support consumer health ecologies.
- Inequities in the insurance markets may affect middle-class workers and provoke regulatory action.

Consumers May Rebel

Rising costs are being shifted to consumers in the midst of a soft economy and loose labor markets. There is a window of opportunity for industry to build incentives for consumers to play a more active role in managing not just their health care, but also their health. If market change is to occur—if consumers are to play along willingly—consumers must believe that the changes offer more choice, greater efficiency and reliability, and meet their personal needs. Consumers will need to see both the immediate and long-term benefit of taking on more responsibility. If progress is too slow, for example if adoption of transparent systems that reveal consumer price–service trade-offs lags, the window of opportunity may close before a critical mass of consumers is truly required to become more engaged. This could come about if an unexpectedly swift and strong economic recovery were to occur. If labor markets tighten, benefits will again become key in recruiting and retaining needed talent, and consumers may rebel, demanding benefits that require them to do less of the hard work and pay less for their health and health care services.

Consumers can rebel in another way—they can opt out of traditional medical care and insurance. Many healthy consumers can take their out-of-pocket cash or health spending accounts and spend them in the broader health market of alternative providers, gyms, and health food stores. They can disengage from health care and so exert less influence over it, leaving the influence to be wielded by motivated sick consumers. Thus significant growth of the consumer-directed models that could facilitate consumer engagement could also erode insurance risk pools, endangering the most needy among us.

Complexity Obfuscates Decision Making

A lot of information is available for making health decisions. Even with the rise of the web-based information tools like Pacific Business Group on Health's HealthScope, or Health-grades.com, Public Citizen's physician rating services, the task of finding out what one needs to know to make sound decisions about providers is daunting. Even for the motivated health consumer, the task of hunting down and evaluating the type of information that would be helpful to make a serious health care decision requires grappling with fragmented and incomplete information, challenging experts, and taking leaps of faith. The complexity of health and health care obfuscates

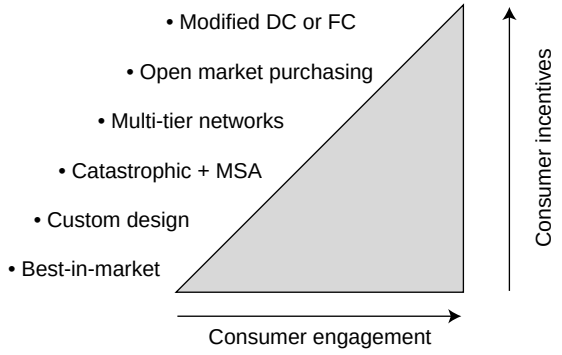
CONSUMER-DIRECTED MODELS OF HEALTH CARE

The discussion of defined-contribution (DC) plans has evolved into an exploration of defined health care and consumer-directed (CD) models—approaches in which the consumer is engaged in decision making and has incentives to make sound economic decisions. When discussing defined-contribution health care, most imagine a health care account (HCA) accompanied by catastrophic health insurance. But Hewitt Associates describes a more articulated model in its 2002 report, *Health Care Expectations: Future Strategy and Direction* (see Figure 3–5).

Hewitt's findings are consistent with IFTF's research on employer-sponsored health benefits: There will be no monolithic model of CD plans over the next ten years. Rather, multiple models will continue to develop that attempt to engage consumers' minds and pocketbooks.

CD models run along a spectrum from low consumer engagement and incentives to models that maximize consumer involvement. The **"best-in-market"** approach, in which employer/purchasers simply survey the market and offer employees coverage that best meets company needs, is at the bottom of that spectrum. Widely practiced today, this strategy offers employees little-to-no choice and few incentives for making value-driven decisions. Higher on the spectrum is **custom design** coverage that allows employees to choose the right level of benefits for them by augmenting a basic plan or choosing from a menu for each covered service.

Figure 3–5
New Consumer-Directed Models



Source: Hewitt Associates, 2002.

The familiar **medical savings account (MSA) + catastrophic insurance** model often used to define defined-contribution typically has a health care account to which employees and/or employers contribute to cover expected and routine health care needs; some cover preventive care. High-deductible catastrophic insurance kicks in for unexpected or large expenses.

Multi-tier networks create consumer incentives by varying the amount the employee pays depending on which providers, drugs, or facilities he or she chooses. A model that some of the auto companies are using now, this has the potential to create incentives based on both cost and quality or value.

Open-market purchasing is akin to the customary and reasonable system used in traditional dental insurance. A fee schedule is set for a set of covered services and consumers pay less out of pocket if they find providers that meet or charge less than that fee. Price is the key and there may be little incentive for value decisions. The hitch is getting the right list of services to price, typically a large obstacle.

In **modified defined-contribution** approaches, the employer/purchaser sets the amount of the benefit and offers employees choices. Employees can then choose an option that is 100 percent covered or pay more out of pocket. This is basically what the Federal Employees Health Benefits Program does now and may be the first strategy that large employers will pursue since it is the least disruptive.

Recently published research suggests that these new models of insurance are gaining a foothold. Though not yet even 1 percent of the insured population, an estimated 1.5 million people were enrolled in 11 plans as of July 2002. For the most part, these plans represent modified defined-contribution, custom design, and MSA + catastrophic models of consumer-directed insurance. While many of these plans are quite young, their customers are large, established insurance companies like CIGNA, Aetna, and Blue Cross and Blue Shield plans.

How these plans will influence the role of consumers, employer costs, and health markets is unknown. In fact, it is simply too early to tell what their impact will be. Health economists doubt the ability of these approaches to solve the social problem of aggregate health spending. In fact, they posit that currently only 4 percent of national health expenditures even have the potential to be subject to consumer-directed approaches.[17] Yet an experiment is under way, one that may pose significant policy, economic, delivery system, and actuarial challenges.[18]

decision making and can thwart true health care engagement.

Take, for example, the case of a woman who was scheduled to have an abdominal aortic aneurysm repaired. The search for information about the hospital and surgeon led her to a portal that noted that aortic aneurysm repair was a volume-sensitive procedure and only hospitals that performed a minimum number per year should be considered. The same site rated the hospital in question, but it didn't provide information on the volume of aneurysm repairs performed there. Clicking down to the procedure at the hospital level just revealed that it was a volume-sensitive procedure. A trip to WebMD did turn up information on the surgeon—his specialty and how many years he'd been in practice, but nothing about his experience in the procedure in question. A call to the quality department of the hospital to find out how many such repairs they did prompted no reply. The same woman was also required to make a choice between two different types of repairs, each carrying different risks, while fearing having a life-threatening rupture if she didn't act quickly.

If health care itself is complex, consider the effect of choosing between traditional Western medicine and complementary and alternative medicine. Only now do we see fledgling efforts to help consumers evaluate both alternative and allopathic approaches to treating illness and maintaining health. One example is Pharmaca in the western United States, a pharmacy that has Western, homeopathic, and other herbal remedies and databases accessible to consumers to see how these different remedies might interact to affect their health. The bridge between allopathic and alternative health will be slow to be built and, in the interim, consumers are increasingly making choices among their options in the absence of reliable information.

Building a Model That Responds to Consumers Is Hard

While the broader market of health goods and services, from fresh foods and heart rate monitors, to gym memberships and the services of dieticians, knows how to work directly with individuals in consumer markets, health care has not really had to. While other industries honed their skills, built consumer communications infrastructures, and developed the business practices to go with them, health care has lagged behind. Health care has responded to the third-party purchasers—employers and governments—that pay the bills. It will take resources, practice, talent, and the right training to accommodate engaged consumers. This retooling will need to affect everything from advice nurse phone lines and billing processes to physician training and clinical practice. Shifting to incorporate a larger business-to-consumer focus is nothing less than culture change.

Inequities Spark Regulation That Strikes Back

Some health policy theorists believe that the shift toward coverage that looks a bit like indemnity insurance with health spending accounts will begin to erode insurance markets. If older and middle-class consumers find themselves unable to afford or find coverage, they may well seek legislative or legal action. We've already seen a spate of managed care regulation at the state level. There is no reason to think that regulation cannot reach new consumer-directed models of care if gross inequities arise. Even now, talk of health care reform is increasing in political circles. If voting, tax-paying members of the public get fed up, talk could turn to action. Such regulation could inhibit growth in benefits structures that result in rising costs for health care for the elderly and the ill.

Endnotes

[1] See, for example, Herzlinger, R. Let's Put Consumers in Charge of Health Care. HBR *OnPoint*, Publication 1415. Harvard Business School Publishing Corporation, 2002. http://explore.hbr.org

[2] Kaiser Family Foundation/Harvard School of Public Health. *National Survey on Consumer Experiences With and Attitudes Toward Health Plans*. Menlo Park, CA: Kaiser Family Foundation, 2001.

[3] Partnership for Solutions. *Chronic Conditions: Making the Case for Ongoing Care*. Baltimore, MD: Johns Hopkins University, 2002.

[4] Agency for Health Care Research and Quality, Medical Expenditure Panel Survey, 2001. www.ahrq.gov.

[5] Kessler, R.C. et al, Long-Term Trends in the Use of Complementary and Alternative Medical Therapies in the United States, *Annals of Internal Medicine* 2001; 135:262–268

[6] See previous note.

[7] Kaiser Family Foundation. Kaiser Health Poll. Menlo Park CA: Kaiser Family Foundation, 2002.

[8] Reed, M., and Trude, S. Who Do You Trust? Americans' Perspectives on Health Care, 1997-2001. *Center for Studying Health System Change Tracking Report, Results From the Community Tracking Study*, No. 3, August 2002.

[9] www.planetfeedback.com.

[10] Horrigan, J., and Rainie, L. Getting Serious Online. Pew Internet & American Life Project, 2002. www.pewinternet.org.

[11] Fox, S., and Rainie, L. Vital Decisions, How Internet Users Decide What information to Trust When They or Their Loved Ones are Sick. Pew Internet & American Life Project, 2002. www.pewinternet.org.

[12] Hibbard, J., and Peters, E. Supporting Informed Consumer Health Decisions: Data Presentation Approaches that Facilitate the Use of Information in Choice. *Annual Review Public Health* 2003; 24,7:1–21.

[13] Hewitt Associates. *Health Care Expectations: Future Strategy and Direction*. Lincolnshire, IL: Hewitt Associates LLC, 2002.

[14] See note 5.

[15] See note 3.

[16] See note 3.

[17] Nichols, L. Can Defined Contribution Health Insurance Reduce Cost Growth? *EBRI Issue Brief*, Number 246, June 2002.

[18] Robinson, J. Renewed Emphasis on Consumer Cost Sharing In Health Insurance Benefit Design. *Health Affairs*, Web Exclusive, www.healthaffairs.org. March 20, 2002.

Chapter 4

How Engaged Consumers Will Change Health & Health Care

Consumer desire for informed choice and control, the greater awareness of health and health care issues that comes with aging and the health care industry's attempts to control costs by promoting consumer responsibility are driving us into an era of health consumerism, in which more consumers are engaged in health and health care decisions. The most successful health and health care product and service providers will recalibrate their thinking away from pure business-to-business relationships to consider the everyday needs of consumers and begin to cultivate responsive business-to-consumer relationships. Having learned to take consumer needs into account, these health and health care industry stakeholders will develop products and services that support consumers in managing their personal health ecologies and their health.

Many segments of the health and wellness industries, and some parts of health care, will operate almost as if they are in a pure retail environment. Regulatory restrictions, consumer and provider preferences, and industry inertia will be a barrier in this shift. There are, however, major opportunities for the health and health care industries to provide meaningful options and solutions for the growing cadre of engaged consumers. While consumer needs and values will shape their demands for goods and services, the industry-driven push to ensure that consumers pay more will help increase consumers' ability and inclination to provoke health markets to respond.

Larger Numbers, More Active

In the next ten years, both the number of engaged consumers and the intensity of their engagement in health and health care will grow. Growth will reflect both industry efforts to shift costs to consumers and changes in consumers' lives that drive them to seek more health services. As the ranks of those with chronic illness grow from an estimated 125 million Americans in 2000 to 149 million in

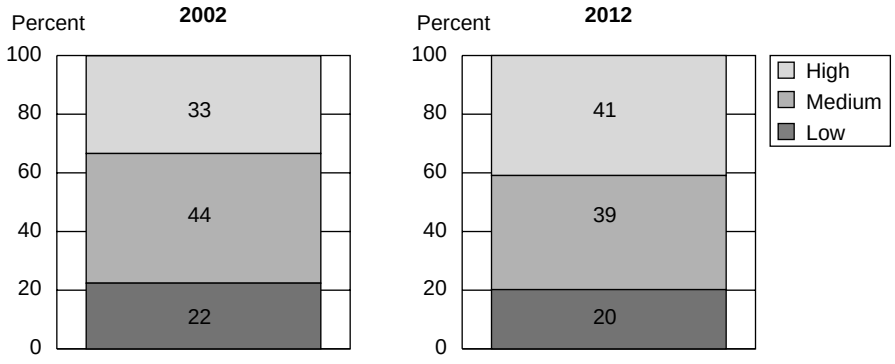
2015, consumers will spend more on health.[1] Experts estimate that innovation in consumer-directed insurance models that offer consumer choice while boosting responsibility for costs will push enrollment to between 15 and 20 percent of the market in the next ten years, increasing the number of health dollars consumers can direct themselves.[2] While there will not be an overwhelming shift of resources from allopathic medicine to alternative medicine, for example, services that were paid for by two different sources of funds will begin to compete head-to-head. As consumers choose where to spend the more than $419 billion they are projected to spend out of pocket by 2012, they will have increasing freedom to go where they get the value they seek.[3] For some services, primary care will compete directly with complementary and alternative medicine providers. These changes will prompt more consumers to make a conscious decision about where to spend their health dollars and to become engaged health consumers.

By 2012 the convergence of these forces will mean that roughly 41 percent of the population will be engaged health consumers, up from 33 percent in 2002 (see Figure 4–1).

Consumer Decision-Support Tools Will Lag

The decision-support tools required to simplify the complex area of health and health care for engaged consumers will develop slowly over the next ten years. Engaged consumers want straightforward information to help them make choices about treatments, providers, and benefits, but that is easier requested than supplied. The complexity of health and health care makes it difficult to cut decisions down to simple facts, not only because health decisions are both cognitive and effective, but also because medicine is an imperfect science. Monumental efforts are under way to institute the practice of evidence-based medicine, and medical error is still a persistent problem that even the experts haven't resolved.[4,5] In the meantime, a complex surgery like a coronary artery bypass

Figure 4–1
Ranks of Engaged Health Consumers Will Grow to 41 Percent of the Population
(Percent of U.S. population by health engagement level)



Source: Institute for the Future, Household Survey 2002.

graft will vary in its quality and risks from hospital to hospital, from person to person. Choosing a surgeon is not like choosing a mechanic. Thus, while great progress will be made in communicating to consumers about plan options and prices, it will be slower going when it comes to offering information they want to choose among providers and treatments when their primary interest is in health outcomes rather than service.

Consumers themselves will begin to come fac to face with the fact that they and the providers who hold their lives in their hands have to make decisions under conditions of uncertainty—about the best things to do, in some cases, and about the outcomes of interventions, in others.

Engaged Consumers Will Push The System to Get Needs Met

Emerging consumer value consciousness reflects how consumers seek to meet their health needs under greater cost pressures. Since the underlying force for consumers is the pursuit of health, not health care, they will seek value from a variety of health resources of which health care is just one. Engaged health consumers are seeking informed choice, efficient and responsive service, credible information sources, providers that demonstrate respect and knowledge, expert help when they need it, and the freedom to focus on health rather than the logistics of health care. Their needs begin in the complex personal health domains that are reflected in the dynamic personal health ecologies they construct to manage them. Given the flexibility to choose and the ability to pay for it, consumers will gravitate to services and goods that support these values.

There is no question that the growing ranks of engaged consumers will make demands on health markets. In clinical encounters, more consumers will require providers to help them assess information and confer on important decisions. They will expect providers to accommodate and respect the friends and family members they bring as advocates. And they will second-guess and ask for confirmation of provider recommendations. They expect web- and e-mail-accessibility and to receive information in a timely manner. And they will complain to service providers and to health care purchasers when they don't get the efficient and responsive service they desire. Ultimately, if they can, they will vote with their feet, changing plans and providers as it suits them.

In response to the rush of direct-to-consumer (DTC) advertising and coverage of scientific breakthroughs in the media, consumers are already demanding access to goods and services—from prescription drugs and diagnostic tests to experimental treatments. The shift that will occur, however, is that engaged health consumers will no longer just be targets of this information, but will begin to use the tools of technology to block it, order it, disseminate it within their social networks, and influence the decisions of their friends and family.

Growing consumer engagement is an opportunity as well. Engaged consumers can be great partners in health and health care whose energies can be harnessed to support adoption of health-promoting behaviors and compliance with medical treatments not only for themselves but also for those within their close circle of family and friends. The influential engaged consumers may be critical and helpful allies for those who provide health goods and services, not only as customers or patients or clients themselves, but also as the health experts upon whom patients and customers rely. The challenge is to begin to focus on these engaged consumers and to enter into partnership with them.

A Perspective Shift in Health Care

The rise of engaged consumers coupled with an increase in their ability to direct health dollars will force a shift in the balance between business-to-business (B2B) and business-to-consumer (B2C) perspectives in health care. Traditionally a predominantly B2B industry, health care has not developed the consumer marketing skills of other industries. That will change over the next ten years and a greater amount of emphasis will be placed on the B2C world. This shift will, perhaps, be a nuance in the next two to three years; seven to ten years out, however, it will result in a shift in the dynamics of health care. Those who succeed will increasingly have to have one foot in the B2B world and one foot in the B2C world. As the balance shifts, products and services will need to differentiate themselves based more on consumer rather than business needs.

How can health care industry players make this shift successfully? They will invest in tools and practices that allow them to listen to consumers and to communicate with them as consumers would like them to. Self-service benefits management will become the norm for employed populations and plans serving them will play along. Very large employers will drive the emergence of comparative price and quality data for specific populations. There will be innovation in the insurance markets in both group and individual markets. (A current example is Wellpoint's Unicare, which offers short-term individual policies that bridge coverage gaps outside of COBRA programs.) A more tiered market will exist as some health market providers tap only the high-end consumers and others distinguish themselves on price.

That is, however, only part of the picture. Since consumers view health broadly, they will be looking for health goods and services, information, and advice in a wide variety of settings, from their primary care provider's office to the grocery store, from the health plan Web site to their martial arts studio. Thus the opportunities to provide health and health care services are diffuse. No one company can or even should play in all of these areas of the health domain, but those who make the shift to a more consumer-focused business will take these areas into account and work with consumers to make decisions based on a holistic view of health. As one of our interview participants said, "I'd like [my health care provider's] decision making to reflect my decision making." Companies that can do that well will have a leg up in the future.

Meeting the Challenge of Engaged Consumers

The coming era of health and health care will be born of the union of two forces: consumers' need to engage in health, and the health care industry's push to control costs by promoting consumer responsibility. Consumers often have complex and challenging personal health ecologies that, in turn, sit in the competing world of household domains. While consumers seek convenience, control and tools to simplify their engagement with health care, insurers and employers are giving consumers some of the work and decision making that many employers currently do for them. An elite set of consumers does want to engage, but they are also the consumers who are more likely to be burdened by health issues and so the industry trend may offer up more responsibility than they wish to shoulder. For this transition to go smoothly, for it to both meet consumer needs and discover whether consumer engagement does control costs, consumers, health and health care providers, health plans, and purchasers will have to change what they do and

how they do it in an effort to serve consumers in navigating their personal health ecologies. We explore these changes in the next chapter as we address the implications of the ascendance of engaged consumers in an age of industry-driven consumerism.

Endnotes

1 Partnership for Solutions. *Chronic Conditions: Making the Case for Ongoing Care*. Baltimore, MD: Johns Hopkins University, 2002.

2 Gabel, J., et al. Consumer-Driven Health Plans: Are They More Than Talk Now? *Health Affairs*, Web Exclusive, www.healthaffairs.org. November 20, 2002. Project Hope, 2002.

3 Institute for the Future estimated 2012 spending based on projections by the Centers for Medicare and Medicaid Services, Office of the Actuary, 2002.

4 Sisk, J. How Are Health Care Organizations Using Clinical Guidelines. *Health Affairs* 1998; 15,5.

5 Medical Mistakes, Mandatory Reporting of Errors Is the First Step Toward Reducing Them. *San Jose Mercury News*. January 5, 2002. www.bayarea.com.

Chapter 5

What the Emergence of Engaged Health Consumers Means

We are at the beginning of a new era of consumer engagement with health and health care. Our experts suggest that this era will take 15 years to reach maturity. In the interim, this rising consumer engagement will affect everything from traditional clinical care and insurance markets to alternative medicine, prompting changes in how all health industry players operate. In this chapter, we both present the implications of the shifting role of consumers and offer practical applications for personal health ecologies. We consider the changes each health marketplace player—patients, providers, plans, purchasers, and policy makers—will need to make in a world in which individuals will behave much more like true consumers and less like beneficiaries in health markets.

Consumers, Patients, and Their Advocates

The ante is being upped for consumers. As they are increasingly required to review their options for insurance, plans, providers, and treatments and to decide what is best for them and how much they will pay for it, consumers are going to have to learn about the complexities and costs of health and health care. For those who rise to the challenge, personal health ecologies will become more complex. The task of navigating personal health ecologies will demand greater vigilance by individual consumers. Consumers, particularly engaged consumers, will find themselves making explicit financial decisions and trade-offs in the health domain. In order to get quality care, consumers will have to take doctors off the pedestal and ask about effectiveness, cost and trade-offs. Consumers—healthy and ill–will have to determine what they truly need and when to splurge on what they want. For engaged consumers to succeed they will need to:

- Face trade-offs in cost and quality head-on.
- Secure trusted advisors in their personal health ecologies.
- Advocate for the right tools to make informed decisions.

Face Trade-Offs in Cost and Quality

Consumers who are daunted by managing the health domain in a self-service world will find the going tough. In the most benign cases, these consumers may under- or over-insure themselves. In the worst cases they may choose low-quality options in pursuit of good prices and have bad health experiences. As an expert on consumer health care decisions noted, "People make the [benefits] decision based on cost, assuming clinical effectiveness. … They assume that the treatment would not be available if it didn't work." At the same time, another expert noted that, "The amount of evidence about how much bad medicine is out there is daunting." Of course, some consumers will be uninsured altogether as consumer contributions even to employer-sponsored plans become unaffordable.

> Today Claritin will go over-the-counter. Tomorrow, people will find out that it is ten times as expensive as Benadryl. The cost didn't change.
>
> *–Health technology marketer and former consumer marketing executive*

> There is a misperception about what health care can do. There is not a general awareness that there are finite resources. We cannot do everything for everyone all of the time, or even the best things for people.
>
> *–Consumer hotline director*

Find a Trusted Advisor

Consumers will seek trusted advisors and tools that help them navigate increasingly complex health ecologies. These may include an electronic system that the consumer maintains to organize medical records and health information and facilitate information sharing among a consumer's personal set of providers. A network of information sources on alternative and allopathic medicines or a formal relationship with a trusted health agent may be in the consumer's bag of tricks. Whether they pay for help or find it informally, consumers will beef up their network resources in a way that allows them to simplify what will be a growing domain of daily life.

Advocate for Information to Make Sound Decisions

As engaged consumers tackle health and health care in an era of industry-induced consumerism, the buyer had best beware. Consumers will have to play the same role they play when buying a car or finding a house-painter, even though they may know less about health goods and services than they do about their cars. For many, that will be truly uncomfortable because it is hard to subject those you want to trust with your life to reference checks and comparison shopping. It will also be difficult because the task is complex.

Consumer advocates will need to help consumers take on this task. Advocates should prime themselves not so much to fight cost shifting, but to work with consumers, understand the dynamics of personal health ecologies, and make sure that the right information and decision tools are there for consumers to make the hard decisions about trade-offs. Advocates should also make sure that the right coaching is available to help consumers evaluate their providers.

PROVIDERS

When we speak of providers we include Western medicine clinicians, clinics and hospitals; device and medication manufacturers; and, in this instance, complementary and alternative medicine providers and consumer products. As engaged health consumers take hold in health care, their impact will ripple out into the adjacent area of CAM. This is true because more of consumers' out-of-pocket budget could be tapped for expenses previously covered through insurance. The result is a more direct trade-off: Do I see the orthopedist or have six weekly chiropractic sessions? As consumers face the trade-offs and begin to ask questions about efficacy and cost, all providers will notice a difference. Providers must prepare to respond by:

> Doctors need to admit what they don't know and recognize that the patient has to have the opportunity to influence the decision since at least half of medicine is not subject to evidence.
>
> *–Health care quality expert consumer researcher and advocate*

- Building responsive systems that support consumers.
- Talking straight about price and quality.
- Becoming coaches and interpreters for engaged consumers.
- Working with personal health ecologies to optimize care.

Build Responsive, Substantive, Consumer Communication Systems

Providers will need to build the capacity to respond quickly to consumer demands if they want to be active participants in a more consumer-directed environment. The clear priority will be bringing health communications in line with those that consumers encounter in other businesses—for example, e-mail or interactive Web sites. The real challenge and the opportunity will be in differentiating provider goods and services in a market that is largely undifferentiated in the eyes of the consumer. Within hospitals, maternity and cardiac care centers have years of direct consumer experience. Understanding how these centers learned about and have implemented consumer preferences could provide insight into how this can be done.

There are many in the worlds of CAM and consumer goods marketing that are adept at speaking to consumers. Not only will their skill take on additional importance, it will compete directly with Western medicine as consumers direct the dollars that flow into medical-savings and flexible-spending accounts to goods and services in consumer markets. Western health care providers can learn from the pharmaceutical industry's direct-to-consumer efforts. One expert notes that health care must find a way to appeal to consumers' hearts as well as their minds because emotion is an important driver of health decisions. Why? Consumers who need health care are looking for someone to take care of them.

Talk Straight About Price and Quality

In order to differentiate themselves, providers are going to need to deal with a few sacred cows as well. As consumers pay more, they want to know the price providers are charging and why, and what competitors charge for the same service. While psychiatric care will not succumb to a sticker price, MRIs, arthroscopic knee surgery and even labor and delivery may. One new consumer-directed health plan

marketer told us that they do the best they can in providing consumers information to make informed provider choices, but the greatest barrier to doing so is the providers themselves, hospitals in particular. Providers have to come to terms with posting their prices. They also have to create a shared vernacular that allows consumers to compare prices across providers. Consumers want to know what an elective surgery will cost them at hospital X versus Hospital Y and what they get for it.

Quality will count more and what providers do and do not say about it will distinguish them among savvy consumers with specific needs. Ten years from now, consumers will want to know more about the quality and value of the service they are getting for their money. Providers will have to wrestle with what is revealed and how it's revealed. Our experts believe that providers should push information to consumers. Holding back information is not only bad for consumers, but also bad for providers themselves. It prevents true partnerships that could bring about better health outcomes and gets in the way of building trusting provider-patient relationships. Those providers who hit upon consumer-friendly approaches to communicate about their own performance and the relative merits of specific treatments may differentiate themselves in the increasingly consumer-focused market.

Plan to Be Coaches and Interpreters

Today there is a plethora of information but no one trusted place to get it. Motivated consumers work their social networks for referrals to providers who are reputed to be good, and gather condition-specific information for diagnosis and treatments. More consumers will come armed with information and want expert counsel in evaluating it and making decisions. As physicians themselves move from being the primary source of information to being one of many, they will have to become guides, coaches, and interpreters.

The implication of taking on the coach and interpreter role is that providers will have to restructure their time. Providers simply cannot do more without altering what they already do. As one expert noted, "A physician's pressed time is a patient's limited time." Consumers want to focus that time on getting assistance in making decisions on care. In order to find the time to interact with consumers as partners in health care, physicians, in particular, will have to learn how to make efficient use of qualified non-physician staff in their offices. Shrewd use of non-physician staff will increase the demand for nurse practitioners and highly proficient RNs in office settings.

Work with Personal Health Ecologies

The personal health ecology (PHE) can be a tool for clinical management. When applied to an individual patient, the PHE can help providers understand the resources a patient has to draw upon, her desired mix of products and services, and the competing health interests he or she has to deal with when it comes to managing an episode of serious acute illness or chronic disease. One can imagine a patient filling out an intake form that incorporates a PHE template. Clinicians could then use the patient's PHE along with their health history and medical records for discharge planning after a hospital stay or to help patients manage chronic disease. Product and service companies could create tools to help providers or caregivers coordinate the many aspects of health and disease management.

If applied to a patient population, personal health ecologies can help characterize the needs of a client base. Most individuals will probably only focus on a handful of priority items in their PHE; a products or service company, or a health plan, or provider wants to fit

into those priorities because in them lie business opportunities. Mapping the core issues in a patient group's PHEs can help providers build the right infrastructure for consumer-centered services—services that must be efficient and responsive, and help consumers navigate these personal health ecologies. For example, by reviewing PHEs a primary care medical group may find that managing multiple medications prescribed by doctors outside of the group is a problem for many of their patients. They could develop simple systems that make it easy for the patient to manage multiple perscriptions from multiple doctors and leaves them feeling in control.

PLANS

Plans are the middlemen between purchasers and consumers and providers and purchasers. They have been seen as being the invisible third party in the exam room. Though this hasn't been a popular position in the recent past, it is a position from which consumer engagement can be encouraged and supported in the most positive ways. Plans can succeed at aiding consumer engagement if they:

- Make consumer-directed plans consumer-centered.
- Help consumers see trade-offs and simplify decisions.
- Help map the middle ground between defined benefit and defined contribution.

Make Consumer-Directed Plans Consumer-Centered

New consumer-directed plans are a real and growing part of the health care landscape, but do they reflect consumers' needs? Yes and no. Many offer consumers choice. That's a good thing. Consumers like choice, but these plans also make consumers work and pay for that choice. While that may result in more cost-conscious choices, it may not be so good from the consumer's perspective. Diffusion theory tells us that the rate at which new technologies and practices—innovations—are adopted depends upon their compatibility with existing values and practices, the flexibility with which they can be used, their reversibility if they don't work out, the relative advantages they possess over existing options, their complexity and cost-efficiency, and the risk they bring.[1] To date, consumer-directed plans have made their case to purchasers, as well they should. As the role of consumers grows, however, they will have to make their case to consumers themselves and take into account how consumers organize health and health care as part of their daily lives.

A glance at the sample personal health ecologies in Chapter 1 shows the need for efficient, trusted sources of information and tools for managing the personal health domain. While no plan can meet every need in a personal health ecology, a plan can certainly meet many of these needs once it has established its credibility. For consumer-directed plans to truly be consumer-centered, they will have to support personal health ecologies. How?

- Make it easy for consumers to see the value that they get from managing their own health benefits.
- Make trade-offs in price and quality and convenience explicit.
- Make consumer-directed plans work with existing benefits tools and resources.
- Realize that lots of consumers are reluctant to manage benefits online and provide flexible tools so that consumers can customize what they want in ways that fit with their lives and values.

Most health care consumers really do not want health management as a new hobby. As one of our consumer experts put it, "Unless you are a fairly intense consumer of health care, health care is not something you think about. One consumer said, 'Who wants to think about health care? It's not fun.'" While it may not be possible to make consumer-directed plans fun, fun may make them meet the criteria for adoption. But those criteria have to reflect consumer reality as well as health plan and provider realities. They need to be simple, cost-effective, compatible with consumers' lives, and flexible, hold relative advantage, and carry reasonable risk from the consumer's perspective.

Help Consumers See Trade-Offs and Simplify Decisions

The lesson of the managed care backlash may well be that consumers need to ration themselves. That is certainly the underlying assumption of cost shifting and the emerging forms of consumer-directed health care. However, plans like their provider counterparts have shied away from making the trade-offs explicit to consumers. As one expert put it, "If plans are going to [lead], they are going to have to step out in front and say what people don't want to hear." For example, plans may have to say that if they must cover the costs of highly expensive treatments that have little scientific evidence of success, they will have to raise prices on the routine services that most people need. This consumer expert went on to say, "If you don't have leaders who have the credibility to say that [the health care industry, policymakers, consumer advocates, and consumers alike] have to make decisions with scarce resources, we will never move from defined benefit to defined contribution."

Find the Middle Ground in the Defined Benefit–Defined Contribution Shift

The shift from defined benefit to defined contribution is more a shift in perspective than a shift in funding mechanisms. Inherent in this shift is the notion that we don't define the benefits people should have as the organizing principle but rather we define how much money there is for health care and let individuals decide how to spend it There is a middle ground, of course, one with which the expert would agree. The middle ground is found in the answers to the questions: What amount of money should we allocate per capita given a minimum acceptable set of benefits? What will we give up if we spend more? Can we live with it? Health plans have been vilified in the managed care saga and that makes them unlikely leaders in framing the issue of trade-offs in health care. Yet plans can, and will, be pushed to make trade-offs explicit. Their success will turn on the degree to which they make trade-offs explicit, involve consumers in exploring them, and create easy mechanisms for those trade-offs to be chosen rather than imposed.

Purchasers

There is unquestionably a window of opportunity for purchasers to change the dynamics of health markets. There is also a threat. If cost shifting and overwhelming responsibility are rammed down the throats of unwilling consumers there could be a backlash as great as or greater than the managed care backlash. If done without regard for the real advantages of risk pooling, purchasers in the small-group market could see health insurance move quickly out of the realm of affordability. Three approaches will help minimize the potential for backlash:

- Building systems with engaged consumers.
- Driving the market to deliver information to support consumers.
- Structuring benefits options to maximize the advantages of group coverage.

Build Consumer-Direct Systems With Consumers

Our experts, the consumers we interviewed, and the literature tell us that consumers want choice and they want control. A consumer-directed health plan would be one that was constructed with consumer input. Purchasers, particularly large employer-purchasers, have the capacity to generate that input. Also, there are tools to help them gather input and engage potential enrollees in the debate about the trade-offs. Sacramento Healthcare Decisions (www.sachealthdecisons.org) offers its Choosing Healthplans All Together (CHAT) workshops for exactly that purpose. Though they are arguably suspect, purchasers are also trusted agents for insured populations. Purchasers are in a position to help consumers wade through the onslaught of new information and emerge wiser users of health goods and services.

Some employers work with union representatives to negotiate benefits. Consumer-directed plans appear to and, in some case, do decrease benefits. Already the burden of higher employee contributions falls heaviest on lower-income workers. Employer-purchasers can show the initiative of working with employee representatives to graduate the burden of employee contributions by adjusting contributions to income.

Personal health ecologies offer a window into consumer needs and desires. One expert suggested that an employer, for example, could determine the distribution of activities in the health domains of its employees, rank their importance and, based on this, design systems that would support employee-managed, mass customization. Short of that, personal health ecologies could be completed by employees themselves, typed and, given an employee's domain management style and the resources in the personal health ecology, used to guide benefits choice. Thus, employees could use their PHEs as a diagnostic tool to help them decide what benefits are right for them. In fact, people do this already. They think about their own health needs and choose benefits accordingly. Structuring a process that allows them to fill in a PHE and, based on the needs and resources it contains, get recommendations for plans, providers and other resources, could offer consumers just the type of decision tool that helps them tailor and simplify decision making.

Force the Market to Deliver the Information to Support the System

There cannot be informed consumers and value-based choices in the absence of comparable information about price and quality. Purchasers have a role to play in making sure this information is available for consumers to make decisions. And, of course, they already are doing this. Organizations such as the Leapfrog Group are painstakingly working to advance a quality agenda and set standards so that purchasers can make value-based decisions. The next step is getting useful and comparable information to consumers. Purchasers are in a perfect position to get consumers to participate in creating the tools that they want and need to support them in their health decisions. Plans and providers will supply needed price and quality information if they are paid to do so. Contracts have to reward those who provide information at a level that covers the cost and the risk of collecting and disseminating quality information. In California,

Integrated Healthcare Association, a managed care trade association, is attempting performance-based contracting with as much as a 10 percent differential in payment based on performance. Purchasers have to construct meaningful incentive structures now to get the information needed to even run the experiment of the effects of consumerism on cost saving.

Remember, most consumers know more about the cars they drive and clothes they wear than they do about the physicians who operate on them or the hospitals in which the surgeries take place. Until very recently, Americans spent more on entertainment than on health care. They are neophytes in exercising the same value assessments in health care as they do in every other realm of their lives. Purchasers are in a strong position to change the dynamic.

Structure Offerings to Maximize Benefits of Group Coverage

There is an ominous side of the move toward consumerism in health. Aside from the obvious potential for people to under-insure, drop insurance altogether as prices rise, or make decisions with a negative impact on their health, there is the risk that healthy people will leave comprehensive group coverage in favor of catastrophic insurance and leave the old, ill, and disabled in comprehensive plans. The cost of plans for such a population would be prohibitive and the threat of loss of insurance or underinsurance would be considerable.

As new, consumer-directed plans gain a foothold, purchasers are in a position to assess their effects on the composition and the actuarial risks of the groups they cover. Purchasers should establish systems that track the dynamics of the risk pool and sound an alarm when corrective action is needed. Purchasers are also in a position to work with insurers to construct plans that ameliorate this risk.

Policy

The policy challenges of the rise of engaged health consumers are complex. In a market in which the products and services address one of our most basic needs, our health, shifting more responsibility to consumers cannot be taken lightly. Policy has the potential to stimulate or stymie information flows, protect or make vulnerable the very sick, and ensure or discourage access to care, among other things. Though policy changes can be sweeping, more typically the changes are slow. The full consequences of such changes, both intended and unintended, are often not felt until long after the policy is implemented. Choices made now will have broad implications and will set the tone for future developments in consumer engagement in health and health care decisions. The policy arena has the potential to address the hazards posed by the dual forces of rising consumer engagement and growing push for consumer responsibility. Here are some of the top policy issues to address on the path to greater direct consumer engagement in health and health care:

- Promoting the availability of standard information on health and health care.
- Fostering health and health care literacy.
- Planning for high- and low-risk pools.
- Anticipating and providing for growth of the uninsured population.

Promoting Availability of Standardized Consumer Information

To make value-based choices, consumers need to be able to compare the cost and quality of different options. They need to know the relative costs and probable outcomes of a coronary artery bypass graft surgery done at Hospital X compared with those at Hospital Y. They need ready access to information about the surgeons and how their patients have

fared. They need to know the price and performance of follow-up care. The health insurance market is already complex. Consumers struggle now to understand their options. What happens as options increase with added incentives to control costs? Even communications about insurance options could be standardized so that consumers can make meaningful comparisons. Working with both consumers and providers to understand what they believe to be the most relevant and accessible indicators of quality will be an important first step. Establishing methods to measure and report this information will be the important role of advocates and policymakers.

Addressing the Affects of Health Literacy on Health Status

Health engagement demands a high level of health literacy from its participants. Health literacy is the ability to understand and consistently act upon health information. Being literate in health can mean giving an informed consent to a treatment or following through with the directions for taking medication or monitoring blood sugar. Even the health-literate elite—those people who are comfortable gathering information from a variety of sources and feel confident and informed when making health decisions—will be better equipped to make these decisions with new tools and techniques for supporting health literacy.

Low health literacy is inequitably distributed among already disadvantaged populations, the sick, the elderly, and ethnic and racial minorities. Health literacy can affect health outcomes substantially.[2] Recent studies have shown that 30 percent of diabetic patients with what was considered "inadequate health literacy" had poor blood sugar control and were more likely to report serious complications than the 20 percent that demonstrated what was considered "adequate" health literacy.

Health literacy is one of the largest underaddressed and critical issues to consider as the decision-making power in health and health care shifts to consumers. Policymakers, in addition to plans and providers, will be faced with growing disparities in health outcomes if tools are not in place to support those who need them. These include simple decision-support tools for insurance and treatment decisions, including health agents and advocates to help people to navigate the health system, and coverage for medical devices that facilitate clinical management in an increasingly self-service world.

The biggest, most influential policy-setting body in health, of course, is not Congress but Medicare. The move toward greater consumerism will be shaped and tempered by what Medicare reimburses. Thus Medicare can make power plays in shaping the kind of information that is available and in what form, the nature of disclosure of costs and quality, and the diffusion of technologies that rely not on literacy but interaction to help those least able to help themselves.

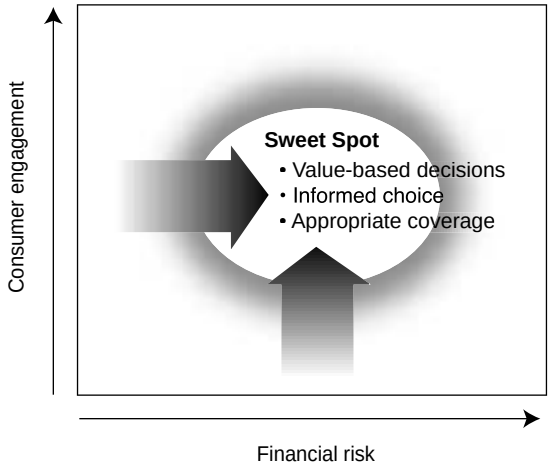
Planning for High- and Low-Risk Insurance Groups

While greater choice means that consumers can pick and choose what fits their needs, it is likely that this will lead to greater segmentation of the insurance market by health status, and some plans will effectively be "cream skimming" (treating all the healthy people) while others will be managing the complex health issues of the chronically ill. As the employment-based risk pools erode, devising mechanisms to plan for managing this increased segmentation by health status will be the work of researchers, advocates and policymakers.

Anticipating the Growing Ranks of the Uninsured

The specter casting a shadow on this emerging era of engaged consumers and more direct consumer markets in health is the uninsured. We know that consumers are price sensitive when it comes to health insurance coverage. Thirty-nine percent of workers with annual incomes of $20,000 or less and 29 percent of those with incomes of $35,000 or less who decline health benefits offered by their employers do so because the benefits are too expensive. Fourteen and 10 percent of employees with annual incomes of $35,000–$59,000 and $60,000 and above, respectively, decline for the same reason.[3] Those percentages are likely to grow as health costs increase. Un-insured and under-insured status will become more prevalent in the middle class over the next two years. As state budgets collapse under the weight of a weak economy, increasing costs of health care (e.g., Medicaid cost increases) and the federal deficit, platforms for supporting the uninsured are likely to weaken. The combination of increased complexity of benefits and opportunities, increased cost to consumers, and the weak economy will incite uninsured working people who vote to demand new policies to provide health care.

Figure 5–1
The Interplay of Financial Risk and Consumer Engagement



Source: Institute for the Future

The Rise of Engaged Consumers—Pluses and Minuses

At this moment, the debate about the rise of consumer engagement in health is hot. We believe it has the potential to bring both good and bad results. There is a sweet spot where consumer engagement and financial risk meet (see Figure 5–1). As one expert puts it, "Until consumers have a greater investment in [health care], they will continue to pressure the system to get what they want. The notion of cost effectiveness doesn't even come into play unless you know the cost." Value judgments cannot come into play unless the probable or expected benefit is known. In the sweet spot, consumers are engaged, informed, and invested in health and health care and can make value-based health decisions that allow them to call on the varied resources in their health ecologies.

We have been in the realm of low consumer engagement and low financial risk. We can see the downside of this realm in over-use or misuse of medical care. One example is the overuse and misuse of penicillin. In a true consumer market, you would not be likely to buy a $56 prescription drug if you were informed that it would not do anything for your viral infection. However, if you are making a $5 or $10 co-pay and there is a remote chance that it is really a bacterial infection and there are no side effects of the drug, why not? Someone else is paying for it. The problem is that overuse drives cost

up and basically means that someone else doesn't get covered. It also has public health effects as we battle drug-resistant disease strains. In the end, it's not in the best interest of the individual or the general public to allocate resources inefficiently.

On the other side of the sweet spot lies a dangerous realm of extreme financial and personal risk in the form of low consumer engagement. In this realm, consumers underinsure, decline insurance, or simply cannot afford to get it in the open market. Those who face high co-pays and deductibles delay care even when they shouldn't. Not only do the ranks of the uninsured grow, but also the health status of the population may decline as those with chronic disease stretch their dollars.

The goal is the sweet spot. The challenges to getting there are great. They involve creating the systems of information and expert advice necessary for informed consumer decisions, full disclosure by plans and providers, and a Herculean effort to meld what has historically been a business-to-business market to accommodate business-to-consumer services. Can it be done? Yes. We stand on the brink of a new experiment in health and health care, we have the opportunity to make it a full and complete one. Health product and service providers, health plans, health care purchasers, and consumers themselves can work together to make sure that engaged consumers have the tools they need to be their own best agents in a world of consumer-driven health and health care.

Endnotes

[1] Orlandi, M., et al. Diffusion of Health Promotion Innovations. In *Health Behavior and Education, Theory, Research, and Practice*. Karen Glanz et al., eds. San Francisco, CA: Jossey-Bass, 1990, pp. 288–313.

[2] Schillinger et al. Association of Health Literacy with Diabetes Outcomes. *Journal of the American Medical Association* 2002; 288:475–482. Baker et al. Functional Health Literacy and the Risk of Hospital Admission Among Medicare Managed Care Enrollees. *AJPH* 2002; 92:1278–1283.

[3] Duchon, L., et al. *Listening to Workers: Challenges for Employer-Sponsored Coverage in the 21st Century*, Publication No. 361. New York, NY: The Commonwealth Fund, 2000.

Appendix

Methodology

Data for this research come from three primary sources as well as the literature cited in this report. These sources are:

- IFTF's 2002 Household Survey
- Semi-structured interviews with health decision makers
- Semi-structured interviews conducted with experts on consumers, health, and health care

2002 Household Survey

This survey, sponsored by IFTF, obtained telephone interviews with a nationally representative sample of 1,502 adults living in households with telephones in the continental United States. The sample was drawn using standard list-assisted random digit dialing methodology, and the interviews were conducted by Princeton Survey Research Associates from May 13 to June 22, 2002, with a response rate of 41%. Statistical results were weighted by sex, age, education, race, Hispanic origin, and region (based upon data from the March 2001 Current Population Survey) to correct known demographic discrepancies. The margin of sampling error for the complete set of weighted data is ±3%.

Construction of the Consumer Health Engagement Index

IFTF used survey data to define a set of individuals whom we called engaged health consumers. We created a three-level health engagement index based on four sets of health behaviors that we believe indicate active pursuit of health. The four behaviors we included were whether or not a person had, within the last 12 months, sought information about alternative treatment options; made a change in their diet in order to be healthier; took nutritional supplements daily; and had spent at least one hour managing his or her own or family's health within the previous week. Those who had none of these behaviors we categorized as displaying low health engagement. Those who had one or two

behaviors, we categorized with medium health engagement. Those who had three or more of these behaviors, we put in the high health engagement category. By integrating this quantitative index with the lessons from our semi-structured interviews, we began to construct a concept of health engagement and describe the characteristics of people across the spectrum.

Health Decision Maker Survey

In the summer of 2002, IFTF researchers interviewed a wide range of health decision makers to capture the broad spectrum of health and health care experience. We spoke mostly with women because they make the lion's share of health decisions. We selected participants who ranged in age from 24 to 78. Some were married with children living in the household, others were single or had grown children. Participants were of Caucasian, Asian, Hispanic, and African descent. There were immigrants and citizens, insured and uninsured among the participants. We interviewed workers and retirees. We spoke with those with high school educations, those with some college, as well as those with college and professional degrees. Among the participants, household incomes ranged from less than $25,000 to $125,000 or more.

Expert Interviews

IFTF researchers conducted two rounds of interviews with experts to assess the veracity, magnitude, pace, and import of the shifting role of consumers in health care and to discuss specific implications of both this shifting role and of the findings from the health decision maker interviews. These experts represent health care providers, plans, health technology companies, consumer advocates, health policymakers, and consumer marketing companies.