



From Patients to Partners: A Consensus Framework for Engaging Californians in Their Health and Health Care

For Release on July 14, 2009

The comments and recommendations in this report do not represent in any way the official positions of the State of California or the California Office of the Patient Advocate.

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Under contract to the California Office of the Patient Advocate

Special Acknowledgements

We acknowledge the special efforts of Richard Adler and Miriam Lueck of the Institute for the Future for their facilitation of the Expert Panel Task Force and the Health Industry Task Force and their preparation of the draft reports summarizing the proceedings of those meetings which addressed concepts and issues incorporated into this report.

We acknowledge the guidance and participation of the Office of the Patient Advocate in this joint effort, including the OPA Director, Sandra Perez, Deputy Director, Ed Mendoza, and Health Education Specialist, Martha Torres-Montoya, all of whom worked closely with us every step of the way since July 2008.

Each and every one of the Task Force members and each of the authors, was special in his or her own way. Additionally, I would also like to note special guidance at key stages of the project that was provided by David Lansky, Pacific Business Group on Health, Dr. David Sobel, Kaiser Permanente Medical Group, and Kate Lorig, Stanford Center for Research in Patient Education. Their thinking and past work were particularly important in helping to frame the issues for this report.

Last, but not least, there are many CPAC staff members who provided special expertise in editing, analysis, group process and intimate understandings of consumers and the health care industry; they included: Ann Munoz, Perfecto Munoz, Donna Fox, Albert LoweyBall, Yovana Gomez, Carol Shepherd McClain, and Louise Halberg.

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Executive Summary

From Washington D.C. to the counties and cities of California, health care reform is in the air.

In our nation's capitol, House and Senate Committees are working feverishly on legislation to expand coverage to the nation's uninsured and overhaul the U.S. health care system by year's end.

Here in California, public and private groups are struggling in the face of an enormous budget crisis to assure affordable health care coverage for all state residents.

Standing at the center of this reform movement is the patient, the health care consumer—the person who uses the health care system to protect and monitor his or her health. Consumers can be more than patients; they can be partners in health care. A consumer who is engaged in her health is a powerful force, with the ability to shape the quality of her own care, help control health care costs, and even shape the way our health care system operates.

The California Program on Access to Care (CPAC), a program of UC Berkeley's School of Public Health, prepared this report on consumer engagement at the behest of California's Office of the Patient Advocate. The Report includes input from over 40 health care "stakeholders," i.e., individuals representing private health plans, physician groups, hospitals, state officials, consumer groups, the media, and the research community. The resulting recommendations detail specific steps that can help consumers play a greater role in improving the quality of their health care, now and in the future.

The Challenge of Engaging Consumers

The process of engaging consumers to become active in their health care starts with an understanding of the challenges consumers currently face. Consumers are expected to undertake a sweeping array of health care tasks, from comparing coverage options when selecting health plans, to finding competent doctors and safe hospitals, to choosing effective treatments and managing their chronic conditions. When faced with the need to make an important decision, consumers may not know where to turn for help or may find misinformation, rather than useful guidance. Sometimes, consumers may freeze up under the weight of complex choices and not act in their own best interest.

Principles to Support Consumer Engagement

The Report shows that health care stakeholders are striving to provide useful guidance to consumers. In order to provide effective guidance, stakeholders first need to know key information about their

consumer audience, such as their age, ethnicity, education and income. Once this information is attained, only then can stakeholders tailor messages to promote specific behavior changes or relay useful information. These messages should be streamlined and should also motivate consumers to take “small steps” on the road to health care engagement and health improvement. The messages need to be promoted in positive ways--ways that enable and persuade--and address consumers’ fears and hopes. Since people are receptive to messages that they help create themselves, health care stakeholders should actively listen to and incorporate ideas suggested by their audience, not just seek to teach their audience.

The use of innovative technologies, such as Internet social networking sites, video-sharing, wikis and blogs, can forge new ways for health care providers and consumers to communicate. New technologies can be balanced with more interpersonal outreach efforts for consumers who prefer getting information directly from other people. Health care stakeholders can collaborate with each other in outreach and promotion campaigns and create bold messages to motivate consumer engagement.

Stakeholders can also try new approaches to engage consumers. The Report highlights a framework for consumer “activation” recently developed by Dr. Judith Hibbard of the University of Oregon. The goal of the activation approach is to build on an individual’s capacity to manage her own health care by assigning discrete tasks that lead to successful outcomes and build consumer confidence. The more confident a consumer becomes in managing her care, the more responsibility the consumer is willing to assume. Dr. Hibbard’s approach seeks to measure a consumer’s activation, tailor support and communications, track progress, and evaluate interventions.

Issues, Action, and Positive Models

As noted in the Report, the four major health care areas where consumers could use a helping hand to become engaged include: 1) navigating the health care system, 2) making choices among health plans and providers, 3) influencing and managing the care they receive, including self-management of chronic disease, and 4) adopting healthy behaviors.

- **Navigating the system:** Health care professionals routinely underestimate the difficulties of navigating the health care system and overestimate the resources and skills that consumers bring to this task. The Report identifies a variety of navigation tools that have been developed and tested in recent years. For example, both public and private health plans have instituted personal coaching programs that use trained advisors or “health coaches,” often known as “promotores,” to work with chronically ill patients. Other helpful navigation tools include using community-based outreach workers to help public program enrollees in Medicare and Medi-Cal to understand benefit options. One promising model highlighted in the Report is the Health Insurance Counseling and Advocacy Program (HICAP), a volunteer-based program administered by the California Department of Aging. HICAP offers free services and confidential counseling on a variety of Medicare topics.
- **Choosing health plans and providers:** Health consumers also face a growing array of decisions related to benefit plan options and costs, including different premium levels, deductibles, co-payments, coinsurance rates, and varying restrictions on provider choice. Developing effective tools to support choice of health plans and providers requires that the consumer audience be clearly defined. It also requires understanding the health care decisions the audience is facing and the context and type of support the decisions require. The Report emphasizes the importance of helping consumers understand and use comparative information about providers and plans. The Report highlights a successful campaign sponsored by the California HealthCare Foundation to encourage use of a website that allows people to compare the quality of care at California’s hospitals.

- **Self-managing chronic conditions:** Consumer engagement is indispensable in the arena of chronic care. The importance of consumer engagement will only continue to increase; for the last 50 years, chronic disease has surpassed acute illness and injury as the leading cause of mortality and morbidity in the United States. Providing care for people with chronic conditions accounts for approximately three-quarters of all health care expenditures in California. Many experts contend that patients and their social networks are their own primary care givers and represent the most important part of the health care delivery team in chronic care. Research also shows that health care providers who are supportive of patient self-management have more activated patients. The Report highlights Stanford's Chronic Disease Self-Management Program (CDSMP), as developed by Dr. Kate Lorig. This program is designed to give patients the knowledge, skills, and confidence to manage their chronic diseases effectively.
- **Engaging in healthy behaviors:** Promoting healthy behaviors on a regular basis is a central element of consumer engagement. This means promoting healthy behaviors before people are in crisis and are forced to navigate the health care environment while under duress. Simply developing a laundry list of dangers associated with unhealthy behaviors tends to be ineffective in persuading people to adopt healthy behaviors. New healthy behavior promotion methods, modeled after the successes of California's tobacco control models, involve campaigns that make it easy for people to engage in healthy behaviors, while making it as difficult as possible to engage in harmful behaviors. Another successful model highlighted in the Report for promoting healthy behaviors is the Critical Mass Health Conductor program, which originated in Oakland. This program encourages African Americans to live healthier lifestyles through participation in support groups and role modeling.

Cross Cutting Strategies to Support Implementations

In order to fully engage consumers as partners in their own health care, cooperation and coordination is required among all health care stakeholders. When collaboration occurs, creativity is unleashed, issues can be viewed from all sides, and practical solutions producing broad impacts can emerge. The Report's Summary Table outlining stakeholder recommendations assumes such active collaborations.

Health care stakeholders also need to promote Health Information Technology, which can provide easy access to usable information, create virtual communities to support self-care management, and link individuals and groups working toward the same goals. Moreover, it is important that health care stakeholders include consumers at board room meetings and at legislative hearings. Stakeholders need to recognize and support the ability of consumers to effectively govern and engage in policy making.

The Report suggests that the greatest challenge in consumer engagement is sustaining effective innovations and replicating them. Studies on health care quality improvement programs show that it is difficult to retain effective new practices for even one year. Those who design and implement new consumer engagement practices will have to develop a certain degree of self-awareness, and learn to involve people who are good observers and good listeners in order to gain clarity about what worked and why so that new successes can be duplicated in other venues.

Many of the concepts and recommendations discussed in the Report can be framed in the context of our country's health care reform movement. Given the pervasiveness of health care reform efforts, we believe our report and recommendations should find a receptive audience. We also believe that implementing the Report's recommendations will provide a path that leads to real successes in consumer engagement and that lays the groundwork for larger changes. The Report recommendations are outlined in the following Summary Table and are detailed in Appendix B at the end of the Report.

SUMMARY OF RECOMMENDATIONS BY STAKEHOLDER GROUP
Cross-Cutting Actions and Key Initiatives by Engagement Domain

	Cross-Cutting Actions	1. Navigating Access to Care and Benefits	2. Choosing Health Plans and Providers	3. Self Managing Chronic Conditions	4. Engaging in Healthy Behaviors
OPA	<p>Expand outreach and coordination role</p> <p>Extend partnerships with stakeholders through revised advisory bodies</p> <p>Expand communications and dissemination through regular conferences and newsletters</p> <p>Cultivate media relations</p>	<p>Facilitate communication and coordination across industry and consumer groups about available navigation tools and resources (e.g., Promotores and patient navigator programs)</p> <p>Promote expansion and use of "211" services</p> <p>Clarify, promote, and expand HEROIC programs</p>	<p>Target performance reports to specific market segments with high impact (e.g., diabetes, asthma, maternity care, heart care)</p> <p>Add "patient stories" to existing performance metrics</p>	<p>Provide referrals to information and programs sponsored by partner stakeholders aimed at helping consumers self manage chronic conditions (e.g., diabetes, depression, autism, etc.)</p>	<p>Provide referrals to information and programs sponsored by partner stakeholders aimed at supporting consumers to engage in healthy behaviors</p>
Health Plans	<p>Realign provider payment methods to encourage greater coordination and integration of care, and patient-centered delivery of services</p>	<p>Develop standard approaches across plans to simplify descriptions of benefits</p> <p>Adopt proven models of personal guidance to enrollees such as the Promotoras program</p>	<p>Collaborate with OPA to identify and collect common metrics for high impact conditions</p>	<p>Create easy to use, accessible personal health records</p>	<p>Develop and implement innovative uses of simple technologies such as mobile phones to support patient engagement</p>
Health Care Providers	<p>Develop patient-provider "compacts" to define roles and responsibilities</p>	<p>Work with OPA and other stakeholders to develop simple checklists of "10 things to do"</p>	<p>Provide patients and families with information about health care coverage alternatives (e.g., California Children's Services)</p>	<p>Sponsor group visits with trained patient facilitators: patients becoming providers</p> <p>Engage patients in shared decision-making</p>	<p>Support training of PCPs as change agents to engage patients in health behaviors</p> <p>Use PAM and related tools</p>
Purchasers	<p>Realign payment methods to plans and providers to encourage coordination and integration of care and services and adoption of evidence-based engagement strategies across the 4 domains</p>	<p>Educate and train employees on how to use the system, through on-site workshops based on adult learning principles</p>	<p>Provide access and training for employees in the use of plan and provider performance reports</p>	<p>Adopt successful models of worksite health promotion</p>	<p>Adopt successful models of worksite health promotion</p>
Consumer Advocates	<p>Serve the role of translator or intermediary to disseminate engagement tools and resources available through OPA and other stakeholders</p> <p>Put pressure on the health industry and other stakeholders to implement recommendations across the 4 domains</p>	<p>Develop or adopt checklists for understanding benefits and access to care</p>	<p>Provide referrals and training for constituent members on how to access and use plan and provider performance reports</p>	<p>Promote self-efficacy and self management programs for chronic conditions.</p>	<p>Advocate for farmers markets in every community to promote access to local, nutritious foods</p>
Media	<p>Use humor and drama and "idea placement" to promote positive engagement behaviors and convey positive messages in entertainment programming</p>	<p>Develop and deliver creative messages through multimedia and PSAs to educate consumers about how to access care and benefits</p>	<p>Collaborate with OPA to promote understanding and use of performance reports on plans and providers</p>	<p>Develop and deliver creative messages through multimedia and PSAs to educate consumers on self-management</p>	<p>Develop and deliver creative messages through multimedia and PSAs to educate consumers on health behaviors</p>

I. Introduction

About the CPAC Consensus Project on Consumer Engagement

The California Program on Access to Care (CPAC), a program at UC Berkeley's School of Public Health, is working with consumers and public and private health care groups to help Californians become more actively engaged in their health and health care. The project goal is to develop a consensus framework, based on recommendations of the academic community, health industry, media, and consumer representatives, to improve and accelerate the consumer engagement process.

CPAC is conducting the Consumer Engagement Project on behalf of the California Office of the Patient Advocate (OPA). We define consumer engagement as the active involvement of patients in their own health care. The Consumer Engagement Project began in December 2008 with a convening of a Health Care Expert Task Force. Health care experts summarized issues and opportunities for enhancing consumer engagement in four major areas:

- Navigating access to care and benefits
- Choosing health plans and providers
- Self-managing chronic conditions
- Engaging in healthy behaviors

In each of these four areas, consumer engagement can contribute to improvements in efficiency, access, effectiveness, and affordability. Consumers who can effectively navigate access to their care and benefits are far less likely to use expensive and yet less effective service delivery settings such as emergency rooms, because they will have learned how to work with a regular physician or "medical home." By choosing high value health plans and providers, consumers can help drive improvements in quality and efficiency. By self-managing chronic conditions, consumers can improve their own outcomes, reduce expensive complications, and live fuller, more productive lives. By engaging in healthy behaviors, consumers can prevent or delay the onset of diseases such as diabetes, heart disease, and cancers that are triggered by unhealthy behaviors. Based on current research and best practices, the task force health care experts also identified a set of principles to guide OPA and other groups in shaping their engagement efforts for maximum effectiveness. (See Section III below). These principles have been refined over the course of the project.

In February 2009, a Health Care Industry Task Force, composed of representatives from providers, purchasers, physician groups, hospitals, commercial plans, the media, and OPA, discussed and contributed to the expert panel's recommendations. In April, 2009, the Consumer-Directed Task Force, composed of advocate organizations and consumer groups as well as media and national advisors, incorporated their ideas and perspectives into the recommendations. The consumer and community viewpoints proved essential in identifying opportunities and barriers related to consumer engagement and in suggesting new approaches for helping consumers make the transition from "patient" to "partners." (Names and affiliations of all project participants are listed in **Appendix A.**)

The final project report, presented in July to consumer advocates, health industry representatives, legislative and executive decision makers and the media at a public informational briefing in Sacramento, synthesize the findings and recommendations from all three task force meetings. This report will be published and widely distributed to multiple audiences inside and outside California.

The aim of this project is two-fold: we want to produce a consensus framework to guide efforts aimed at helping Californians become more actively engaged in their health care, and we want to stimulate strong, coordinated action that connects consumers with health care providers, purchasers, and policy

makers to provide the tools, training, and support needed by all Californians to become more actively engaged in their health and health care. Although the project was originally undertaken to assist the efforts of OPA, it is now clear that genuine and sustained consumer engagement will require the combined efforts of all health care stakeholders. We hope that this Sacramento briefing will generate a call to action for furthering constructive consumer engagement. Our final recommendations are organized by stakeholder group and are listed in the report Summary Table and outlined in **Appendix B**.

II. The Value and Challenge of Engaging Consumers

Consumers who are more involved in their own health care have better health outcomes and lower costs. What does it mean to be an "engaged" health care consumer? A partial listing of the behaviors currently expected of engaged consumers includes:

- Comparing coverage options when selecting health plans
- Selecting competent doctors and safe hospitals
- Making and keeping appointments with providers
- Establishing a relationship with a primary care provider
- Learning a health plan's "ground rules" for using care
- Resolving problems involving health insurance benefits
- Interacting successfully with health professionals and institutions
- Finding and using appropriate health information sources, online or through organizational networks, to inform choices
- Choosing effective treatments
- Following recommendations for promoting personal health (such as diet, exercise, quitting smoking, limiting alcohol use, wearing seat belts)
- Getting screened at appropriate intervals (for cancer and other conditions)
- Taking medications as directed
- Managing chronic conditions to prevent declining health
- Maintaining accurate records for a personal medical history

While some individuals may perform many of these behaviors, it is likely that many individuals do not. Like the vast majority of Americans, many Californians do not even realize that they are expected to act in these ways. Other individuals are unable to take on these expected behaviors because they lack the information, skills, cognitive or physical abilities, or material resources to do so.¹ Engaging California's consumers is potentially complicated by the reality that more than one-third of the state's population has a high school education or less, or does not speak English as a first language. These education and language issues can hamper conventional education outreach efforts and compromise communications with health care providers.

Numerous public and private sector initiatives attempt to help consumers become more involved with and make better decisions about their health and health care. But these efforts are largely uncoordinated, addressing scattered audiences with fragmentary messages. Even where useful information exists, it may not be accessible when and where it is needed. Many people across the state are unaware of available information and tools that can support their health care engagement. Many are also unaware of how health care engagement can be of benefit to them and their families.

What consumers actually want from health care, and the criteria they use in making choices about that care, may be quite different than the criteria identified by "experts." When faced with the need to make an important decision, consumers may not know where to turn for help or may find misinformation, rather than useful guidance. Given the cultural and linguistic diversity in the state, and

the proportion of the population with only basic literacy, information is too often written at a level of language (English or other) which assumes a higher education than many in the intended audience actually have. Some Californians, such as those from the Hmong community, have a language that is only spoken, not written. Furthermore, many people at all education levels prefer to get their information without having to read; therefore, “non- text” communication needs to be added to our outreach repertoire.

III. Overarching Design Principles to Support Effective Consumer Engagement

Guided by our expert panel, the Consumer Engagement Project has identified a core set of overarching design principles to support effective consumer engagement. These principles are based on demonstrated theory and practice from several fields, and have a history of proven effectiveness. In many ways, these theories require all of us to change the “mental model” we often have in approaching patients, consumers, and plan members. The traditional model is that: (1) health care practitioners impart knowledge to consumers; (2) consumers understand and trust what the health professionals say; and (3) consumers follow what health practitioners tell them to do.

However, there is ample evidence that: (1) health care professionals often don’t know enough about individual consumers, or groups of consumers (particularly those from cultures unfamiliar to them) to provide accurate information and useful advice; (2) consumers often have real difficulty understanding what health professionals tell them and distrust the health professional’s information when such information is at odds with what consumers know from other sources; (3) many consumers often do not understand the intricate details of their health plans and what steps to take when they face insurance-based barriers to getting needed care; and (4) consumers often do not follow health advice about such things as getting more exercise, getting screening tests, taking prescribed medications regularly, or tracking health conditions, such as monitoring blood sugar levels.

We believe all our efforts will be more effective if those seeking to engage patients/consumers are guided by the six principles listed below. These principles are relevant to the efforts of the Office of the Patient Advocate, as well as other state agencies, health plans, providers, consumer groups, and stakeholders involved in creating and supporting engaged health consumers. The six overarching design principles to support effective consumer engagement are:

1. Know Your Audience

Delivering messages that persuade and activate consumers requires a detailed understanding of the broad and diverse audiences that OPA and other stakeholders must reach. It is critical to identify and segment the audience to make sure that messages are appropriate for each audience type. For example, key insights can come from knowing consumers’ education and income levels, gender, age, ethnicity, health, and insurance status, and family situation. Interventions must also be linguistically, culturally, and historically relevant for each intended audience.

There are differences in consumers’ level of activation (engagement) in their health. Moreover, consumers’ interest level varies over time. Different types of messages are appropriate at each level of activation and at different times in a consumer’s life. Tailoring education and outreach to consumers who are facing specific health decisions, like choosing a doctor or a health plan, or making a choice about treatment of a serious health condition, and who are ready (in terms of their activation level) to engage in education outreach is more effective than developing generic education and outreach for mass audiences.

2. Tailor Messages to Promote Specific Engagement Behaviors

Health professionals should work with creative communication experts and adult learning experts to create messages encouraging consumers to take small steps on the road to health improvement. It is easy for individuals to get overwhelmed if messages are too complex or daunting. Messages should help consumers build a sense of self-confidence and empowerment, and should motivate consumers to expand their health care responsibilities. Messages are most effective when they build a sense of self-confidence, which people need to experience success. Successful experiences, in turn, make future efforts more likely to succeed. Careful analysis is required to break down courses of action into the smallest and simplest steps.

3. Create Tools (Approaches) That Enable, Don't Prescribe; That Persuade, Don't Lecture

Interventions and information should enable people to take care of themselves and each other, and reaffirm and expand their ability to navigate health care services. Often, health care professional *tell* patients and consumers what they should do, rather than ask patients what *they* want to achieve and then help patients achieve it. Ironically, the *telling* approach is all too often embedded in efforts that are designed to increase consumer engagement, which only serves to reinforce the mistaken notion that only the health professional has the knowledge and the skill to effect health care change.

Information by itself rarely motivates people to act; advertisers and marketers understand this concept well. Promoters of consumer engagement can learn useful lessons from social marketers about how to frame and package persuasive messages that appeal to emotions rather than just to a body of "facts." This emotional connection is a powerful motivational force. Moreover, messages on how to navigate the health care system must be coupled with actual support and necessary infrastructure to enable successful consumer engagement. There are a myriad ways to provide supportive infrastructure, many of which are highlighted in this report. Examples include the use of telephone hotlines and personal advisors as well as the use of virtual support groups. Clearly, multiple approaches to providing supportive infrastructure will be needed, given our state's cultural diversity and the range of health care issues consumers need to address.

4. If *They* Build It, They Will Come

Web-based information sharing models, collectively known as Web 2.0., are innovative and effective ways of reaching out to consumers. OPA and other agencies and stakeholders must move away from strategies that build on the traditional publishing model in which gatekeepers create and distribute messages for a mass audience. People are receptive to messages that they help create themselves. People are also interested in campaigns that are done in partnership with them rather than done unilaterally for them. Health providers and stakeholders should actively listen to their audience, not just teach them. In forging new communication methods, health providers may find it useful to incorporate Internet social-networking sites, video-sharing sites, wikis, and blogs. However, given the continuing presence of the "digital divide," especially for older adults, it would be a mistake to depend entirely on the Web as a channel of communication. Remember that before the Internet, there was another powerful web, the web of personal connections between individuals and their family, friends, and community members. The participants in these webs, as well as community leaders and even popular role models, can help ensure that the messages we communicate are appropriate, motivating, and trusted.

5. Build on the Existing Health Care System to Create and Support Engaged Health Consumers

The entire health system needs to be actively re-aligned to support and reward consumers' engagement. Until a system-wide realignment occurs both public and private sector groups, including providers, practitioners, health plans, and state agencies, must join forces to empower consumers.

In California, the public sector can act through mandated agencies like the Office of the Patient Advocate, the Departments of Managed Care and Insurance, and the Department of Health Care Services, which administers the Medi-Cal program. By setting the parameters for change through regulation and reimbursement, these agencies set rules and constraints for public and private sectors alike.

Many private sector groups, including the provider community and the health plan industry, are already implementing creative and effective consumer engagement programs. Yet, too often they act in isolation, disconnected from each other with little collaboration or cross learning. The project's Task Force process and the resulting report will hopefully serve to stimulate more collaborative efforts within and between the public and private sectors.

Even among consumer groups advocating for greater consumer engagement there is an urgent need to support dialogue and mutual learning. Many consumer groups operate in seclusion, not knowing that others are pursuing the same goals, or have developed innovative practices that are "replicable."

6. Focus on Activating Patients/Consumers

A framework for patient activation, recently developed by Judith Hibbard of the University of Oregon, provides a useful tool to measure patient/consumer activation, tailor support and communications, track progress, and evaluate interventions.² Accurate insights about patient competencies for self-management, and reliable measures for tracking progress have proven to be essential for effective patient support, yet often have been absent from the health care process. Based on the insights gained from measuring activation, it is possible to tailor support for the individual. For example, we know that patients who are low in activation feel overwhelmed with the task of managing their own health and "freeze up," often doing nothing to help themselves. Allowing patients to focus on only one health improvement at a time often "unfreezes" them and helps them to start taking action. Pushing low activated people to do more than they are ready to do just keeps them in their "frozen" position. The goal of the activation approach is to build an individual's capacity to manage his or her own health and health care.

IV. Domains of Action, Issues and Positive Models

What can be done to support consumers to become more actively engaged in managing their health and making more informed decisions about their health care? This paper examines the four major health care domains explored by the project's Expert Task Force.

1. Navigating Access to Care and Benefits

Health care professionals routinely underestimate the difficulties of navigating the health care system and overestimate the resources and skills that consumers bring to this task. Our current health care system is generally quite good at specializing to provide optimum care for discrete medical problems. However, our system often fails to coordinate care from multiple providers working with the same patient, or to communicate about services that are available for supporting consumers and their

caregivers in managing complex conditions. The consequences of failure to coordinate can be serious. When patients and caregivers have difficulty navigating access to care and services, they often respond by delaying care, failing to get needed care, or seeking care in very expensive settings, such as emergency rooms, that are easily accessible. Furthermore, complex processes for determining eligibility and applying for health care coverage can keep people from getting the health benefits that are available to them. All of these factors can exacerbate health disparities and increase health care costs.

Clearly, consumers need better “maps” to navigate through the health system. Maps need to support consumers’ access to information about benefits and services available to them. Can useful maps be created for such a complex and fragmented system? It may well be that a single, one size fits all map will not work; we may need to create different maps for people facing different health conditions or personal circumstances. Someone with breast cancer may need a different map to navigate the health care system than someone with asthma. Someone who speaks only Korean will certainly need a different map than someone who speaks fluent English.

In recent years, a variety of navigation tools have been developed and tested. For example, both public and private health plans have instituted personal counseling or coaching programs that use trained advisors, or “health coaches,” to work with chronically ill patients. Other helpful navigation tools include using community-based outreach workers to help public program enrollees in Medicare and Medi-Cal understand benefit options, adding health information hot-lines in employer benefits offices, and organizing health training seminars at work sites or in community settings. Technology, including mobile phones which are now being used by 85 percent of all adults, can also play a positive role by expanding access to personal health records and an array of useful guides. Helping consumers navigate the health system entails distilling messages into clear, essential components and presenting messages in multiple media and in forms that are easily accessible and understood by the intended audiences.

Ultimately, comprehensive health system reform efforts are needed to improve coordination and integration of care and services. However, until comprehensive reform happens, it is imperative to focus on strategies that make the health system more transparent and manageable for individuals.

A Promising Model: HICAP

The Health Insurance Counseling and Advocacy Program (HICAP) assists Medicare beneficiaries in making informed choices and provides advocacy when their health care benefits and rights are threatened or denied. The program is supported by the State and by Medicare. This volunteer-based program is administered by the California Department of Aging and is offered in every county in California. HICAP offers free services and confidential counseling on a variety of Medicare topics, including Medicare benefits and rights, changes in Medicare and Medicare-related coverage, how to appeal Medicare fee-for-service and HMO denials of coverage, legal help and representation at Medicare appeals and administrative hearings, private supplemental insurance (MediGap) coverage, Medicare and Medi-Cal coverage, Medicare Advantage plans (also known as Medicare HMOs), retiree or employer group health coverage, long-term care insurance, health care consumer rights, and referral to community-based social and aging program services. The California Health Advocates website provides a complete list of HICAP contacts in every county. The program does not sell, recommend, or endorse any insurance product, agent, insurance company, or health plan. The volunteer counselors receive many hours of intensive and continuous training and are registered with the State of California. Beneficiaries can either make individual appointments by phone or online. Counselors also make house calls for the home-bound. People can learn about HICAP on various websites, and by calling the 1-800-Medicare hotline.

2. Choosing Health Plans and Providers

Californians are facing an unprecedented diversity of health care options, which entails a plethora of health care choices. In traditional plan offerings, employed consumers are generally faced with an annual “open enrollment” decision to renew or change health plans. Employed consumers may need to select among various plans and once selected, need to understand and follow the health plan’s ground rules for receiving care. Medicare beneficiaries must choose between enrolling in the traditional Medicare program or enrolling in a Medicare Advantage managed care plan. Medicare enrollees must also decide whether to choose a prescription drug coverage plan and whether to supplement their Medicare benefits with an additional private plan. Medi-Cal enrollees sometimes must choose between traditional fee-for-service plans and managed care plans.

Almost all health consumers face a growing array of decisions related to benefit plan options and costs, including different premium levels, deductibles, co-payments, coinsurance rates, and varying levels of network restriction. The availability of “consumer-directed” health plans with high deductibles has led to even greater demand for plan members to make choices about whether and when to use their benefits, and how to find the highest-value providers. Once enrolled in a health plan, consumers must select specific health care providers, including doctors, hospitals, and specialists.

There is a growing public and non-profit effort to provide consumers with objective “report card” information about health plans and providers. However, the report card information is not always user-friendly. Different report cards use different performance measures to assess the quality of health plans and providers, thus creating more confusion than clarity for consumers. Many consumer guides are overly complex and technical in their content and design, and do not present information in a way that makes it easy for the public to readily understand differences in performance, or understand which plans and providers are the best match for their individual needs and preferences. Report card sponsors need to strive to incorporate features that have been demonstrated to make report cards much easier for consumers to understand and use. There are several current efforts to detail these features; model reports have also been created to help guide sponsors. Even when comparative quality reports are well designed, they seldom receive effective social marketing promotion so the intended audiences are often unaware of information.

Developing effective tools to support consumers’ choice of health plans and providers requires that the consumer audience be clearly defined. It also requires understanding the health care decisions the audience is facing and the context and type of support the decisions require. Research shows that consumers tend to make decisions based on emotions rather than logic. The science of social marketing recognizes that people respond to messages highlighting clear and immediate benefits. Understanding people’s motivations and the social contexts that support their decision-making is critical to influencing their decisions and their behavior.

It is also important to make health information available at the times and places where it is most relevant and useful for consumers. Someone traveling in an ambulance after suffering a heart attack is not in a good position to make an informed choice about which hospital emergency room to select. On the other hand, an expectant mother does have the time – and the motivation – to consider where she wishes to give birth. A recent pilot campaign sponsored by the California HealthCare Foundation demonstrated that targeting expectant mothers with comparative information about hospital birthing services was highly effective in drawing this audience to a decision support tool.

A Promising Model: Promoting CalHospitalCompare

The California Healthcare Foundation (CHCF) has been a key player in the development of CalHospitalCompare.org, a website that allows people to compare the quality of care at California's hospitals. Much of the initial traffic on the site was from health care professionals rather than consumers, CHCF initiated a pilot marketing project to encourage women of childbearing age in the San Francisco Bay Area who would be interested in hospital performance around childbirth to use the website. The Bay Area region has a high concentration of hospitals participating in CalHospitalCompare, which enhanced the information base available to consumers seeking out maternity services.

CHCF employed a range of online methods to test and compare the cost-efficiency and effectiveness of the pilot outreach campaign. The campaign ran from June through December 2008.

Lessons learned from the pilot project include:

***Consumers will use quality data online if the information is targeted and communicated "where" people go online.** The CHCF on-line campaign drove the use of CalHospitalCompare dramatically and visits to the Bay Area hospital maternity pages substantially increased.*

***Message targeting is key to success.** The campaign communicated specific information about the hospitals providing maternity services in the target market area, information relevant to the target market.*

***There is diversity within a target group of consumers.** It is valuable to offer a range of ads which may appeal to different audiences.*

***Placement location matters.** Search engine placements (such as Google and Yahoo) were more effective approaches to driving use of the site; news site placements drove awareness of the site, but did not translate directly into higher use..*

***Measure, Learn and Re-align.** Campaigns that continuously monitor on-line marketing results can reallocate resources to messages and web sites that are the most cost effective at reaching target audiences.*

Creative use of "non-traditional channels" (such as television comedies and dramas) to support consumer decision making is another promising avenue for targeted communication. Vulnerable populations, in particular, require personal intermediaries such as *promotores* to help with health care choices.

OPA and other agencies should use people's everyday communications channels to create "shockable" and "shoppable" moments, not just "teachable" moments. Stories that travel through social networks can be the most powerful communication devices. In the current economic climate, with increasing concern over the possibility of job loss leading to the possibility of insurance coverage loss, the time may be right for OPA to promote the use of decision support tools and to emphasize that health care decisions are important, understandable, and empowering.

3. Self-Managing Chronic Conditions

Consumer engagement is indispensable in the arena of chronic care; for the last 50 years, chronic disease has surpassed acute illness and injury as the leading cause of mortality and morbidity in the United States. Providing care for people with chronic conditions accounts for approximately three-quarters of all health care expenditures in California. Controlling the cost of chronic care is therefore a high priority for any health care reform proposal, incremental or comprehensive, and improving chronic care definitely requires patients to be more actively involved in their own care.

Many experts contend that patients and their social networks are their own primary care givers and represent the most important part of the health care delivery team in chronic care. People need to be well-informed to partner in their own care and to commit to self-care and preventive behaviors. One self-management approach suggests that achieving consumer engagement is not only a matter of getting people's attention through social marketing, but also of "activating" people's involvement. The process of activation involves a multi-step journey where people take ownership of their health and health care and progressively engage in more complex and challenging healthy behaviors. Interactions with primary care providers are key to positively reinforcing activation.

It is possible to measure activation by measuring a patient's knowledge, skills, and confidence and to use the activation assessment to tailor support for the individual. The State of Washington used this approach with high-risk, long-term disabled Medicaid patients. Results showed that patients receiving tailored support had better outcomes and lower costs than patients who did not receive tailored support.

Research also shows that providers who are supportive of patient self-management have more activated patients. Therefore, it is important to encourage providers to support their patients in developing self-management skills.

Health care researchers at Kaiser Permanente have concluded that, when it comes to dealing with chronic conditions, patients should not be seen as "consumers" of health care, but as the primary "providers" of health care. Kaiser Permanente pilot projects demonstrated improved health outcomes by focusing on changing patient attitudes and building patient confidence in coping with chronic conditions. To encourage greater involvement in self-care, Kaiser Permanente implemented a program called Healthy Living with Ongoing Conditions based on Stanford's Chronic Disease Self-Management Program.

Chronic Disease Self-Management Program (CDSMP)

CDSMP is based on a self-help theory that suggests patients armed with knowledge, skills, and confidence can effectively manage the symptoms of their chronic disease. The program involves having small groups of people with a chronic disease meet together for six weeks. Two leaders, one or both of whom may have similar health problems, facilitate the groups. The groups are interactive and members focus on building skills, sharing experiences, and providing mutual support in the daily management of chronic illness symptoms.

CDSMP was designed in the 1990s by Kate Lorig at the Stanford Center for Research in Patient Education. Before the CDSMP project was disseminated for implementation, Stanford researchers evaluated its effectiveness in four phases: a six-month randomized clinical trial; a two-year longitudinal study; a dissemination/replication study; and a qualitative study of the implementation process. All studies have been published in peer-review journals.³ All have confirmed that the program improves health-enhancing behavior, health status, and health care utilization/costs for participants. The program has been disseminated widely through several Kaiser Permanente regions.⁴

Increasing consumer involvement in health care will work only if physicians and other health professionals support the goal. Therefore, Kaiser Permanente developed a series of on-line and in-person training programs aimed at its own staff titled "Motivating Change." As a community service, Kaiser Permanente makes the on-line training programs available to any health professional. The online programs can be accessed at www.kphealtheducation.org.

While these strategies may work well in the context of a large HMO, can they be translated to smaller, traditional practices? Leaders at Kaiser believe that 80 percent of Kaiser Permanente's initiatives should work in other settings.

The most effective strategies for HMOs, physicians, and government agencies to achieve improved health outcomes is to focus on giving people practical, actionable help in dealing with specific needs and problems. The key message for the OPA and other State agencies reiterates one of our design principles: "If *they* build it, they will come." Messages that are co-produced by providers and patients resonate more powerfully than messages developed by providers alone. Supporting patient efforts to help themselves is at the heart of consumer engagement.

4. Engaging in Healthy Behaviors

Promoting healthy behaviors on a regular basis is a central element of consumer engagement. This means promoting healthy behaviors before people are in crisis and are forced to navigate the health care environment while under duress. Engaging in healthy behaviors also increases the degree to which consumers feel in charge of their health, a key enabler for many of the strategies recommended in other areas. Indeed, health promotion efforts are popular partly because promotion efforts do make people feel empowered. While the initial responsibility for engaging consumers in healthy behaviors starts in the realm of public health, prevention efforts sponsored by private health plans and employers in the name of reducing costs are also important venues.

Workplace health promotion is the current “new thing” (although the idea has been around for decades) attracting considerable attention from employers who recognize that there is a real link between employees’ health status and their productivity on the job. But workplace health promotion is not a panacea. In fact, employees who get involved in workplace programs tend to be the people who are already inclined to engage in healthy behaviors, while the employees with the most health problems tend not to engage in workplace programs.

Health risk assessments, which are currently popular among employers, are often not effective in motivating positive change. Many employees have figured out how to “game” these programs and say what employers want to hear. In addition, there is a real danger of a backlash from workers who see workplace health promotion as an employer’s intrusion in their private lives. Finally, most health promotion programs are designed for large employers, and may not be workable for small companies even though small companies employ a large proportion of California’s workforce. Ironically, workplace health programs may actually work to increase disparities between those who are already healthy and those who are most vulnerable to health problems, unless the programs (1) are implemented by small and medium sized businesses, many of whom employ low-income workers, and (2) are designed and promoted to be of benefit and interest to workers who are initially less motivated to get engaged with their own health.

The workplace, however, is not the only setting for health promotion efforts; health promotion efforts need to be carried out across the community. An intriguing approach to community wide efforts is to consider what can be done to make it as easy as possible for people to engage in healthy behaviors, while making it as difficult as possible to engage in harmful behaviors. Tobacco control efforts, which are among the most successful in the history of health promotion, focused on policy interventions as well as major media campaigns to make it more difficult to smoke and to normalize not using tobacco. It became more difficult and expensive to buy cigarettes and smoke them, especially in public. In contrast, traditional approaches that told people about the dangers of smoking didn’t work. Reframing health promotion campaigns is an ongoing challenge. For example, anti-obesity campaigns need to be reframed because messages about the dangers of being overweight and the merits of exercise and healthy eating are not working and the problem of obesity continues to grow.

The use of “indirect” interventions also shows promise. One anti-obesity initiative aimed at helping overweight teenage girls lose weight was billed as an after-school dance program. Instead of junk food and soda, the program offered healthy snacks and water. After 18 months, girls in the dance program showed greater weight loss than girls in a control group. Some indirect interventions involve redesigning jobs and work flow patterns to incorporate more physical activity. Rather than focus explicitly on promoting health, these programs ask employees to consider ways to make their work more effective and their jobs more satisfying.

Another non-traditional approach to fighting obesity and poor diet involves bringing farmers’ markets to low-income areas lacking access to healthy foods. The underlying lesson here is that taking

healthy, desirable options to people is more effective than asking people to go out of their way to achieve a goal, even if the goal is “good for them.”

Efforts to change behaviors are always difficult and the journey is sometimes painful. However, if you have a guide to assist you, and a support group and a role model to emulate, it can make it easier to change. Consider the Critical Mass Health Conductors (CMHC) model.

A Promising Model – Critical Mass Health Conductors

In 2005, Critical Mass Health Conductors (CMHC) was launched at the 2nd African American Health Summit in Oakland, California. The purpose of CMHC is to encourage African Americans to make good health choices. Conductors are dedicated to live healthy lifestyles, and influence the health behavior of family members, friends, and the community. To become a Health Conductor, a person joins a support group and commits to achieving a health goal over the course of a four-month journey. Health Conductors learn practical ways to achieve their health goals by making positive health choices and lifestyle decisions. Some of these goals include increased exercise, better nutrition, weight reduction, positive mental health, stress reduction, and solid sleep. Participants help each other get past the stumbling blocks encountered on the road to health improvement and celebrate healthy lifestyle successes. At monthly gatherings, Health Conductor trainees learn about stress management, the “metabolic syndrome,” and ways to reduce dietary fats and sugars. Trainees participate in movement activities and sample a variety of healthy foods. At the end of the four month training journey there is a graduation where each person receives a Health Conductor number joining a group (or movement) of people dedicated to improving their own health and the health of the African American community. These new graduates begin recruiting new Health Conductors-in-training to participate in the next training cycle. In the tradition of Harriet Tubman and the “Underground Railroad,” Health Conductors are building an “Overground Railroad” of freedom from chronic diseases by embracing positive health practices.

V. Cross Cutting Strategies to Support Widespread Implementation

Fully engaging consumers and patients as partners in their own health and health care management requires widespread implementation of innovative strategies. Engagement is particularly needed for those patients in high-risk groups due to low-income, education, language, and chronic conditions. Action is needed on two levels: 1) the micro level of patients’ individual encounters with the health care system, and 2) the macro level of national and statewide health care reform. Below we discuss five major issues in the process of moving toward more effective consumer engagement.

1. Working Collaboratively Across Stakeholder Groups

To meet the challenges of consumer engagement, cooperation and coordination will be required among stakeholders. California’s individual health plans, physicians, provider systems, consumer advocacy groups and state, local, and non-profit agencies are all promoting quality health and health care through productive consumer engagement. However, these groups are often unaware of each other’s efforts, and unaware that they can learn from and benefit each other. Collaboration is also critical if we are to move beyond the health care “blame game” in which one group blames others for performance deficits rather than looking to help others maximize performance results. Collaboration should also include partnering with the media. Too often the media is viewed by stakeholders as a sideline player rather than a potential partner.

It takes hard work to produce consumer engagement in health care. However, our task force meetings reflected a real appetite among various stakeholders’ for working together. When collaboration occurs, creativity is unleashed, issues can be viewed from all sides, and practical solutions producing broad impacts can emerge. Our final recommendations, while directed to each key stakeholder group, also assume active collaborations.

2. Taking Advantage of Health Information Technology

Health Information Technology (IT) is not the complete solution to the problems plaguing our current health care system, but it is an important part of the solution. IT has to be viewed as going far beyond the electronic medical record, or even the personal medical record. IT needs to be viewed in terms of imaginative ways health care consumers can interact with the virtual world and the real world of community, family, providers, and policy makers.

The next few years are likely to see a burgeoning of health IT initiatives, all of which can have an impact by: (1) simplifying the health care system, making it more transparent to the user, facilitating connections and transitions; and making it easier to navigate; (2) providing easy access to usable information to support choice of plans and providers, and usable information for treatments and other interventions; (3) helping create virtual communities to support self-care management and efforts to live in a healthy way, while creating new, timely, and efficient ways for patients and clinicians to connect; and (4) linking individuals and groups who are working on consumer engagement so they understand the most current issues and challenges, and the most current creative ideas and solutions. But IT will only work if the technology is “user centered.” The IT focus needs to move away from static and one-way technologies to mobile and dynamic technologies that allow for a give and take between people.

3. Enhancing Consumer Voice

Consumer engagement is traditionally viewed as a micro level matter, taking place among individuals, or between families or small groups. There is, however, a macro level of consumer engagement, in which consumers are actively involved in governance and policy making. Going back to the design principle “If *they* build it, they will come,” consumers are more likely to engage in a health system that they understand--not as outsiders, but as insiders. That system is far more likely to offer services and messages that resonate with consumers if consumers are at the table in the board rooms, and in legislative hearings while policy level decisions are crafted.

Consumers activated at the macro level are often in the best position to understand how to engage consumers and patients at the micro level. Conversely, people who have become activated at the micro level by having worked on their own health issues are often willing to step up into the policy arena and address the health issues being faced by those with similar conditions.

We have noted that physicians and other clinicians need to support patients in taking steps to become more engaged. We also need to support consumers more effectively as they take on broader roles in governance and policy-making. Consumers need training and information to get beyond the wall of “professional expertise.” Consciously or unconsciously, professionals often build walls when interacting with those they consider “ignorant.” We need to acknowledge the consumers’ expertise and talent. We need to make sure consumers have opportunities to expand their expertise into areas often viewed as too clinical or technical. The ability of consumers to effectively govern and engage in policy making is exemplified by California’s very productive consumer advocates.

4. Sustaining Best Practices and Bringing Them to Scale

Perhaps the greatest challenge in consumer engagement is not identifying creative solutions or implementing new ones. Rather, the greatest challenge is sustaining effective innovations and replicating them. We know from studies on health care quality improvement programs that it is difficult to retain effective new for even one year.

Sustaining best practices in consumer engagement means strategies need to be robust and not dependent on a single charismatic leader, a small staff of extremely committed people, a short-term

infusion of funds, or any other “unique” circumstances. It also implies that we have to keep track of what really makes new practices work well. Most of the time, it will not be possible to conduct highly rigorous and formal evaluations to identify these key elements, such as has been done with an intervention like the Stanford Chronic Disease Self-Management Model. Instead, those who design and implement new consumer engagement practices will have to develop a certain degree of self-awareness, and learn to involve people who are good observers and good listeners in order to gain clarity about what worked, and why. Information about successful strategies will then need to be broadly shared. We need to encourage a “culture of shameless stealing” in which ideas are shared and success is measured by how often you are imitated.

5. Taking Advantage of the Health Reform “Moment”

There is a growing recognition of the importance of consumer engagement. A recent report on the concept of a “patient-centered medical home” stated that there must be a “recognition that patients are not the object of care, but rather they are full-fledged participants in it – and unless that participation is active and informed, the impact of health care, whether services, drugs, surgery or devices, is severely muted.”⁵ Numerous studies suggest considerable health care savings can be derived by substantial reforms in the four domains described in this report. Yet, in current health care reform debate at both the state and national levels, consumer engagement is viewed as a secondary issue.

At the state level, consumer engagement efforts can start with State agencies recognizing when their audiences overlap and collaborating to align their messages and resources. Collaboration can occur even in the face of dire budget deficits due to the current economic recession. Although the State may not be able to take advantage of Federal Stimulus programs to expand health care coverage to individuals with chronic illnesses or to individuals recently uninsured due to employment loss, the State can still encourage consumers to engage in the health care reform movement. California’s public and private health care agencies can coordinate their efforts to prepare consumers at all economic and educational levels to be a partner in health care changes.

At the national level, the Obama administration is building support for health care reform by inspiring individuals to participate in community discussion groups. About 8,000 local health care discussion groups have already been organized. Summaries from the discussion sessions formed the basis of a recent report which analyzed American’s views regarding problems in the U.S. health care system and proposed solutions. This report was presented to the President and is available via the Web. This experience demonstrates that Americans from all walks of life, and from all states in the country, desire to participate actively in important policy dialogues as long as they believe their voice will be heard.

Media organizations can also play a key role to increase engagement and promote large-scale, consumer-focused health care reforms. The media can partner with government agencies and the health care industry to convey messages that support the concept of consumer engagement and promote healthy behaviors. Stories that feature celebrities and influential people can be particularly effective in reinforcing positive messages about the benefits of becoming an engaged consumer.

Many of the concepts and recommendations discussed in this report can be framed in the context of our country’s health care reform “moment.” In fact, with health care reform “in the air,” our report and recommendations should find a receptive audience. We believe that implementing our recommendations will provide a path that leads to real successes in consumer engagement and that lays the groundwork for larger changes.

¹ Gruman, J. et. al. *A New Definition of Patient Engagement: What is Engagement and Why is it Important?*, Center for Advancing Health, October 2008.

² Hibbard, J., Stockard, J., Mahoney, E., Tusler, M. 2004. Development of the patient activation measure Conceptualizing and measuring activation in patients and consumers, HSR. Health Services Research. 39:4, Part 1.

³ Sobel, David S., Kate R. Lorig, and Mary Hobbs, 2002. "Chronic Disease Self-Management Program: From Development to Dissemination." *The Permanente Journal* 6(2). Accessed 10-6-08 at <http://xnet.kp.org/permanentejournal/spring02/selfmanage.html>.

⁴ More information on the CDSMP can be found at <http://patienteducation.stanford.edu/programs>.

⁵ Gruman, J. and Jeffress D., *Supporting Patient Engagement in the Patient-Centered Medical Home*, Center for Advancing Health, 2008.

General Reference List on Consumer Engagement

AHRQ Health Care Innovations Exchange. (2008). Online Tools and Services Activate Plan Enrollees and Engage Them in Their Care, Enhance Efficiency, and Improve Satisfaction and Retention. Accessed June, 25, 2009, from <http://www.innovations.ahrq.gov/content.aspx?id=2133>.

Arnold, S., & Scanlon, D.P. (2009). Realizing True Consumer-Directed Health Care: What the Policy Community Needs. *Medical Care Research and Review*, 66(1), 3S - 8S. Accessed June 25, 2009, from http://mcr.sagepub.com/cgi/reprint/66/1_suppl/3S?rss=1

Bond, M.T., Heshizer, B.P., Knapp, D.E., & Pesta, B.J. (2007). Experience With Consumer-Driven Health Plans: Does the Performance of High-Deductible Health Plans Match Expectations? *Compensation & Benefits Review*, 39(3), 60-68. doi: 10.1177/0886368707302647

Deloitte Center for Health Solutions, The. (2008). Connected care: technology-enabled care at home. Accessed June 25, 2009 from http://www.deloitte.com/dtt/cda/doc/content/us_chs_ConnectedCare_final_0308.pdf

Deloitte Center for Health Solutions. (2008). Consumer-Directed Health Plans: Current Trends, Emerging Opportunities. Accessed June 25, 2009, from http://www.deloitte.com/dtt/cda/doc/content/us_chs_consumerdirectedhealthplans_1207_v1w.pdf

Deloitte Center for Health Solutions, The. (2008). Opportunities for Health Plans in a Consumer-Driven Market: A Point of View Based on Deloitte's 2008 Survey of Health Care Consumers. Accessed June 25, 2009 from <http://www.deloitte.com/dtt/article/0%2C1002%2Ccid%25253D212937%2C00.html>

Deloitte Center for Health Solutions, The. (2008). The Medical Home: Disruptive Innovation for a New Primary Care Model. Accessed June 25, 2009 from <http://www.deloitte.com/dtt/article/0%2C1002%2Ccid%25253D186574%2C00.html>

Emont, N., & Emont, S. (2007). Advancing eHealth-- Opportunities and Challenges for Health e-Technologies Initiative: Findings from Interviews & Surveys of Opinion Leaders & Stakeholders. Accessed June 25, 2009, from <http://www.rwjf.org/files/research/385941048advancingehealthopportunities.pdf>

Henry J. Kaiser Family Foundation, The. (2008). Emerging Health Information Technology for Children in Medicaid and SCHIP Programs. The Children's Partnership and The Kaiser Commission on Medicaid and the Uninsured. Accessed June 25, 2009 from <http://www.kff.org/medicaid/upload/7837.pdf>

Hibbard J.H., Mahoney, E.R., Stock, R., & Tusler, M. (2007). Self-Management and Health Care Utilization: Do Increases in Patient Activation Result in Improved Self-Management Behaviors? *Health Service Research*. 42(4), 1443-1463. doi: 10.1111/j.1475-6773.2006.00669.x

Hibbard, J.H., & Cunningham, P.J. (2008). How Engaged are Consumers in Their Health and Health Care, and Why Does it Matter? *Center for Studying Health System Change*. 8. Accessed on June 25, 2009 from <http://www.rwjf.org/files/research/101608.rb8.pdf>

Hibbard, J.H. (2009). Using systematic measurement to target consumer activation strategies. *Medical Care Research and Review*, 66(1), 95-275. Accessed June 25, 2009, from http://mcr.sagepub.com/cgi/content/abstract/66/1_suppl/9S

Hurley, R.E., Keenan, P.S., Martsof, G.D., Maeng, D.D., & Scanlon, D.P. (2008). Early experiences with consumer engagement initiatives to improve chronic care. *Health Affairs*, 28(1), 277-283. Accessed June 25, 2009 from <http://content.healthaffairs.org/cgi/content/full/28/1/277?ijkey=IcGprEwgF7CtY&keytype=ref&siteid=healthaff>

Manhatt Health Solutions. (2008). Whose Data is it Anyway? Expanding Consumer Control over Personal Health Information. Accessed June 25, 2009, from <http://www.chcf.org/documents/chronicdisease/WhoseDataIsItAnywayIB.pdf>

McCarthy, D., Mueller, K., & Tillmann, I. (2009). Group Health Cooperative: Reinventing Primary Care by Connecting Patients with a Medical Home. The Commonwealth Fund. Accessed June 25, 2009 from <http://www.commonwealthfund.org/Content/Publications/Case-Studies/2009/Jun/Group-Health-Cooperative.aspx#citation>

National Working Group on Evidence-Based Healthcare. (2008). The Role of the Patient/Consumer in Establishing a Dynamic Clinical Research Continuum: Models of Patient/Consumer Inclusion. Accessed June 25, 2009 from <http://www.evidencebasedhealthcare.org/>

Neuhauser, L., & Kreps, G. (2003). Rethinking Communication in the E-Health Era. *Journal of Health Psychology*. 8(1), 7-23. doi: 10.1177/1359105303008001426

Partnership for Quality Care. (2008). *Case Studies of Innovations in Chronic Care to Improve Outcomes and Contain Healthcare Costs*. Accessed June 25, 2009, from <http://www.pqc-usa.org/docs/report.pdf>.

Ranganathan, M., Hibbard, J.H., Conroy, K., de Brantes, F., Rodday, A.M., et al. (2009). Motivating Public Use of Physician-Level Performance Data: An Experiment on the Effects of Message and Mode. *Medical Care Research and Review*, 66(1), 68-81. doi: 10.1177/1077558708324301

Robert Wood Johnson Foundation. (2007). Aligning Forces for Quality First Annual Meeting and Consumer Engagement Learning Community Meeting: Meeting Highlights. Accessed June 25, 2009, from <http://www.rwjf.org/files/research/af4qmtgreport2007.pdf>

Robert Wood Johnson Foundation. (2009). Aligning Forces for Quality: Community Snapshots: Accessed June 25, 2009, from <http://www.rwjf.org/pr/product.jsp?id=42249>

Seidman, J. & Eytan, T. (2008). Helping Patients Plug In: Lessons in the Adoption of Online Consumer Tools. California Health Care Foundation. Accessed June 25, 2009 from <http://www.chcf.org/topics/view.cfm?itemid=133659>

Sepucha, K. & Mulley, A. (2009). A Perspective on the Patient's Role in Treatment Decisions. *Medical Care Research and Review*, 66(1), 535-574. doi: 10.1177/1077558708325511

- Shaller, D. (2007). Consumer Engagement: Whose Responsibility Is It? *American Journal of Medical Quality*, 22(5), 309 - 310. Accessed June 25, 2009, from <http://ajm.sagepub.com/cgi/content/refs/22/5/309>
- Shaller Consulting. (2006). Consumers in Health Care: Creating Decision-Support Tools that Work. California Health Care Foundation. Accessed June 25, 2009, from <http://www.chcf.org/documents/insurance/CreatingDecisionSupportTools.pdf>
- Shaller, D. (2005). Consumers in Health Care: The Burden of Choice. California Health Care Foundation. Accessed June 25, 2009, from <http://www.chcf.org/topics/view.cfm?itemID=115327>
- Shaller D, Hoy E, and Onstad, K. (2003). Designing Consumer Guides for Medi-Cal Managed Care Beneficiaries. California HealthCare Foundation. Accessed June 25, 2009 from <http://www.chcf.org/documents/consumer/ConsumerGuideDesign.pdf>
- Shaller, D., Soafer, S., Findlay, S., Hibbard, J. H., Lansky, D., & Delbanco, S. (2003). Consumers And Quality-Driven Health Care: A Call To Action. *Health Affairs*, 22(2), 95-101
doi: 10.1377/hlthaff.22.2.95
- Shea, B., Santesso, N., Qualman, A., Heiberg ,T., Leong, A., Judd, M., Robinson, V., et al. (2005). Consumer-driven health care: building partnerships in research. *Health Expectations*, 8(4), 352-359. Accessed June 25, 2009, from <http://www3.interscience.wiley.com/journal/118712214/abstract>
Navigation
- Sofaer, S. (2009). Navigating Poorly Charted Territory: Patient Dilemmas in Health Care "Nonsystems". *Medical Care Research and Review*, 66(1) , 75S-93S. doi: 10.1177/1077558708327945
- Thomson R., Murtagh, M., Khaw, F.M. (2005). Tensions in public health policy: patient engagement, evidence-based public health and health inequalities. *Quality and Safety in Health Care*, 14, 396-400. doi:10.1136/qshc.2005.014175
- Williams, S. & Heller, A. (2007). Patient activation among Medicare beneficiaries: Segmentation to promote informed health care decision making. *International Journal of Pharmaceutical and Healthcare Marketing*, 1(3), 199-213. doi: 10.1108/17506120710818210

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APPENDIX B

**From Patients to Partners:
A Consensus Framework for Engaging Californians in Their Health and Health Care**

Consumer Engagement Recommendations

Listed below are targeted recommendations for OPA, Health Plans, Health Care Providers, Purchasers, Consumer Advocacy Groups, and the Media. These recommendations are derived from the input of three task force discussions on the topic of consumer engagement. Task force members included researchers, physicians, health care advocates, community representatives, the media, and other stakeholder groups.

I. Office of the Patient Advocate (OPA)

- *OPA should focus on coordinating and maximizing opportunities in the health care arena.* Given its limited resources, OPA should seek to fulfill its mission of informing and educating consumers by coordinating with other groups. Through expanded outreach and partnerships, OPA can elevate its visibility and brand identity to become a trusted "go to" resource. OPA must connect people with problem solving resources.
- *Rebrand the OPA identity to revitalize OPA's image.* Rebranding will make OPA's mission and functions more clear and vital to the public as well as to stakeholder partners. A starting point would be to emphasize two or three key benefits provided by OPA in the form of a tagline, such as: *Outreach, Information, Engagement*. OPA should seek strategic guidance on marketing and branding ideas from experts in the field.
- *Review and revise the role of OPA advisory bodies.* The organizations represented on the Health Industry and Consumer Task Forces could provide valuable continuity and goodwill in moving forward with an expanded coordination role. Creating an ongoing vehicle for advisory input will reinforce communication, buy-in, and ownership, and extend OPA's reach to other industry and consumer groups.
- *Sponsor an annual or bi-annual "state of engagement" conference.* The conference would profile OPA and highlight the work of its expanding network of partners in the health industry and consumer advocacy communities.
- *Develop a regular e-newsletter or "engagement update."* An electronic newsletter will serve to maintain public visibility, introduce new reports, highlight engagement activities of partner organizations, and publicize resources and tools for stakeholder organizations to use with their consumer audiences. OPA could also use the e-newsletter to provide information about the newly expanding area of over-the-counter devices to test, monitor, and treat medical conditions. It's important to push this material out on a regular basis, since websites are passive.
- *Constantly cultivate relationships with the media.* Media outreach will showcase and promote OPA resources and encourage broadcast media to use OPA as a "go to" resource for educational and entertainment programming.

Specific program initiatives OPA should consider include the following:

- *Promote the expansion of 211 call center services.* OPA should explore venues to promote the expansion of 211 services into additional counties and publicize the value of using of 211 services to receive timely health care information or to connect to needed health services.
- *Highlight the role and function of its HEROIC programs.* OPA should explain the goals of the HMO Enrollee Regional Outreach and Information Centers (HEROIC) programs and promote success stories of how HEROIC has helped people. Consider expanding the number and mix of HEROIC programs, perhaps by including some of the groups represented on the Consumer Task Force.
- *Work with health plans and medical groups to develop condition-specific performance reports.* For example, develop performance reports related to chronic conditions, such as diabetes, asthma, cancer, and heart conditions, which will attract specific segments of consumers and patients and will be more valuable than the generalized measures of plan and group performance reports currently available. [See related Health Plan recommendation below]
- *Work with health plans and medical groups to promote health information on Internet social networking sites.* Using web-based sites, such as YouTube, Twitter, and Facebook, will also help OPA connect with younger audiences.
- *Add "patient stories" to the existing plan and medical group performance reports.* OPA should seek to create a compelling consumer "voice" and personal narratives to underscore the performance report statistics. Patient stories can highlight problems and offer action plans to solve problems.
- *Promote ways to put real people behind 800 numbers.* Doing so will provide a human touch to information and assistance lines in public agencies and private sector organizations.
- *Provide referrals to information and programs sponsored by OPA partner organizations.* Given its resource constraints, OPA cannot be all things to all people. For the engagement domains that are not priority topics for OPA, such as self-management of chronic conditions and engaging in health behaviors, OPA should help connect consumers to the tools and resources provided by other stakeholders.

II. Health Plans

- *Develop standardized approaches for specifying benefits and services.* Health plans should find a simplified approach to explain benefits and services to current and prospective enrollees and to detail ground rules for using services and benefits. Developing standardized specifications may require creating a statewide task force representing the public and private health plans. OPA could play a convening role in this effort, which would allow OPA to showcase its substantial explanatory website material pertaining to benefits and services.
- *Adopt and implement personal guidance models to assist enrollees.* Personal guidance models, such as the Promotores programs, are especially helpful in reaching disadvantaged populations. The primary goal of the promotores program is to encourage clients to become their own health masters and then pass their knowledge on to others. Other people-intensive engagement strategies include the use of health coaches, nurse navigators, and patient navigators. These coaches and navigators can help consumers find their way through the medical maze and obtain appropriate services. Several health plans (e.g., Humana, HealthPartners, and Kaiser) are already implementing such models. These models could serve as prototypes for other plans to use or adapt.

- *Collaborate with OPA to identify, collect, and report common metrics for specific high-impact conditions.* Consumers and patients are more prone to access and use specific condition report cards than generalized report cards that provide overall ratings. An example of a specific condition report card is the D5 website sponsored by Minnesota Community Measurement, which provides self-care guidance to diabetes patients, as well as comparative performance measures on medical groups and clinics treating diabetes patients. (<http://www.thed5.org/>)
- *Develop and implement innovative uses of mobile phone technology to communicate with enrollees.* Hand-held communication devices can receive information about benefits, services, preventive screening reminders, and chronic condition management. This technology could also be linked to innovative use of personal health records, especially for populations that lack access to personal computers, since cell technology is widespread and relatively cheap and easy to use.
- *Promote integration of care by realigning payment methods to health care providers.* Payment realignment can encourage coordination and integration of care and services to patients across multiple providers. Payment should also be structured to create incentives for other patient-centered methods of care delivery, such as the patient-centered medical home model. Large purchasers will need to be supportive of this strategy, and should provide leadership for such payment reform. [See related Purchaser recommendations below]

III. Health Care Providers

- *Work with OPA and health plans in a statewide effort to develop simple patient based checklists.* Such checklist titles could begin with the rubric of "10 Things to Do" such as prepare for an office visit, address questions to your doctor, etc. It is important to make these lists available to all patients through multiple media outlets, in multiple languages, and in multiple locations, including the vast network of community-based organizations. OPA can act as a catalyst to involve community groups and consumer organizations in this process.
- *Provide patients and families with information on coverage alternatives.* Providers treating disadvantaged patients and those without insurance should make patients aware of public programs such as California's Children Services that can help finance needed access to care and services.
- *Sponsor patient-led facilitator groups for other patients.* Use trained patient facilitators to conduct classes aimed at motivating patients to become providers of care for themselves and others. See <http://patienteducation.stanford.edu/programs>.

Improve clinician-patient communication by training clinicians to use techniques that increase collaborative communication and increase motivation for successful behavior change (in individual counseling and in groups). Kaiser Permanente has developed a series of in person and online training programs aimed at its own staff titled "Motivating Change." The online versions of these training programs for health professionals are available as a community service of Kaiser Permanente to any health professional. The online programs can be accessed at www.kphealtheducation.org.

- *Adopt physician-patient "pacts."* These pacts should clearly define the roles and responsibilities of patients and their primary care doctor in working together to promote health and manage disease conditions. A model for patient-clinician pacts can be found at: http://www.cfah.org/pdfs/PACT_White_Paper_120708.pdf.

- *Support training of Primary Care Practitioners as change agents for patients.* Providers need to make sure the Primary Care Practitioners have the tools they need to support patient behavior change interventions, such as losing weight and quitting smoking. A key resource for this activity is the Patient Activation Measure (PAM) and related tools, now offered through a private company started by the University of Oregon: (<http://www.insigniahealth.com/products/pam.html>) Additional resources for improving the patient's experience of care can be found at: <http://www.massgeneral.org/stoecklecenter/services/treatmentprogram.aspx?id=1119> and <https://www.cahps.ahrq.gov/qiguide/default.aspx>.
- *Expand current efforts to engage patients in shared decision making about their health and health care.* Such efforts need to use evidence-based decision tools that are available in the public domain. A major national resource for decision support tools is the Foundation for Informed Decision Making. (<http://www.informedmedicaldecisions.org/index.html>).
- *Adopt current and emerging health information technologies that show promise for engaging patients.* Promising technologies include telemedicine, electronic health records, personal health records, and patient portals for online secure communication with providers and access to information and advice.

IV. Purchasers

- *Educate and train employees on how to navigate the health care system and effectively use services.* Training programs should use simple, standardized materials developed in collaboration with OPA, their health plans, and providers. Purchasers should go beyond merely distributing materials and try to engage groups of employees in on-site, on-the-job training workshops.
- *Teach employees how to use health plan and provider performance reports.* Training tools are available through OPA, and can be customized by employers to fit their specific markets and populations.
- *Adopt successful models of worksite health promotion.* Health promotion models need to be practical for both large and small employer settings. Models should also work well in individual employer settings or in collaborative settings with multiple employers.
- *Realign payment methods to health plans and health care providers.* The central role for purchasers is to structure payment incentives that promote the kind of plan and provider behavior desired. Payment realignment will encourage coordination and integration of care and services to patients across multiple providers, and encourage adoption of evidence-based engagement strategies. These evidence-based strategies are identified in this paper under Section II titled Health Plan, and Section III titled Health Care Provider.

V. Consumer Advocacy Groups

- *Serve the role of "translator" or "intermediary" to disseminate the information to specific audiences.* Advocacy groups can use the tools available through OPA and other stakeholders to reach specific constituencies while making use of appropriate language and communication techniques for each constituency.

- *Connect people to resources.* Advocacy groups can provide the personal connection often absent in the industry, and can link people to the specific tools and resources they need. The HICAP and Promotores programs provide useful prototypes for in-person support activity. Advocacy groups should also provide information and training on how to access and use performance reports and other engagement resources.
- *Pressure the health industry to implement the recommendations outlined in this paper.* Pressure can be applied through public education and through advocacy and lobbying where appropriate. This is a particularly relevant role for patient advocacy groups focusing on specific conditions such as heart disease, cancer, and diabetes.
- *Advocate for farmer's markets in every community.* Introducing farmer's markets in specific neighborhoods promotes access to local, nutritious, and healthy foods.

VI. Media

- *Work with the health community to promote positive consumer engagement.* Broadcast and print journalism should use both humor and drama to promote positive engagement behaviors and to publicize the availability of health resources.
- *Creatively convey positive messages about what consumers can do to become engaged in their health and health care.* The entertainment industry, primarily headquartered in Los Angeles, should go beyond product placement to embrace "idea placement" as a way to creatively convey positive messages about what consumers can do to become engaged in their health and health care. Also needed are messages about what health plans and providers should be doing to promote patient engagement. Examples of idea placement in the entertainment industry have included *As Good As It Gets* (2001) and some progressive TV medical dramas such as *House*.
- *Connect people to health care groups.* The major broadcast and print media should use their health website pages to provide direct linkages to OPA's on-line information and other public and non-profit on-line health sources.