Allies for Quality:
Defining Consumer Perspectives on Health Care Quality

June 2003

This is the first of a series of four briefs from the evaluation of the California HealthCare Foundation’s Allies for Quality program. Each brief will address one aspect of the experience of patient and consumer groups in improving health care quality, highlighting the strategies and concepts arising from the work of the Allies for Quality grantees and ultimately identifying ways patient and consumer groups can work to improve health care quality.

Background
The California HealthCare Foundation (CHCF) established the Quality Initiative in 1998 to improve health care quality in California. Since then, the Quality Initiative has been a catalyst in stimulating consumer-driven improvement of health care quality by fostering the development and dissemination of salient and standardized quality-of-care measures; stimulating consumer and purchaser use of comparative quality information; reducing barriers to quality measurement; and engaging consumers, patients, their representative organizations, the health care industry, purchasers, and policymakers in efforts to improve health care quality.

From the outset, the Foundation recognized that for quality improvement efforts to be consumer-driven, consumer and patient organizations must play a pivotal role. In 2001, the Quality Initiative funded Allies for Quality: Patient and Consumer Groups Improving Health Care, a three-year, $2 million grant program designed to support and encourage the involvement of these organizations in issues of health care quality. Eight grants were awarded to a diverse group of consumer and patient organizations working to improve quality for California’s health care consumers in a variety of ways.

Overview
Recent reports from the Institute of Medicine addressing medical errors and other serious problems with health care quality have generated media coverage and focused public attention on the quality of health care.

Several definitions of quality and ways to measure quality exist. A challenge for the health care system is the continued development and systematic application of meaningful quality improvements. Consumers are an often-overlooked component of this effort. Understanding how consumers perceive quality provides useful insight into how consumer organizations might advocate for improvements.

Consumers and patients bring valuable perspectives and expertise to quality improvement. For consumers, quality is often framed by personal experiences with care and includes, but extends beyond, the clinical aspects of care. This brief describes the work the Allies for Quality grantees
are doing to address the problems faced by their constituents. It also identifies some commonalities across their work, suggesting roles patient and consumer groups can play in improving health care.

Table 1 displays the Allies for Quality Program Model. It is based on the program strategies being implemented by the eight grantees. It describes how the grantees’ collective efforts are working to achieve the ultimate goal of improved quality of care for California consumers. Specifically, it articulates the types of audiences the programs intend to influence, the types of interventions they are implementing, and the intermediate and longer-term outcomes they expect to achieve. The model demonstrates how other consumer organizations can define and address these issues.

### Defining Quality to Improve It

Each of the grantees is working with specific quality issues in a variety of ways. Table 2 summarizes the problems each grantee is addressing and their work to improve quality. This information is drawn from data collected from each of the eight Allies for Quality grantees, including interviews with stakeholders identified by the projects. Each group’s work emerges directly from the types of quality problems identified by their consumer constituents.

The work of the grantees is organized around five major dimensions of health care quality of particular importance to each grantee’s consumer constituents. The following section describes the experience and approach of the grantees within each of these dimensions.

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<th>Table 1. Allies for Quality Program Model</th>
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<td><strong>AUDIENCE</strong></td>
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<td>Consumers, Patients, and Communities</td>
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<td>Providers</td>
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<td>Hospitals and Health Plans</td>
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<td>Policymakers, Other Decision-makers, and Funders</td>
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<td>State Agencies regulating and overseeing health care quality, hospitals, and health plans</td>
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1. Eliminating Discrimination in Health Care Delivery
Grantees have identified biases and stigmas based on racial or ethnic identity, disabilities, insurance status, socioeconomic status, and other characteristics that can affect providers’ perceptions of patients, thereby influencing or altering a patient’s ability to obtain quality care. Grantees are addressing discrimination in two ways: (1) by training intermediaries (community members, institutional staff, other patients) to identify discriminatory practices and attitudes and encourage change through communication with providers and the health care delivery system on behalf of their clients; and (2) by educating consumers directly about their diseases, their rights and responsibilities in the health care system, and ways to advocate for better medical care and improved communication with their providers. These groups are also informing providers directly about patient needs.

2. Increasing the Cultural Competence of Health Care Delivery
Several grantees are working with communities that they find to be underserved by the health care system due to barriers related to cultural differences. The barriers experienced include provider and institutional insensitivity or unresponsiveness to the cultural belief systems and language limitations of monolingual, immigrant populations. These grantees are working to expand local health care delivery to utilize peer support counselors, community health workers (CHW), promotoras (community health workers who originate from and are integrated into Latino communities), and lay educators in order to increase access to culturally competent, language-appropriate, and ethnically relevant care. The projects are also advocating for incorporating these workers as valued, paid, and supported positions in the health care system. A few grantees are also recruiting, training, and supporting their own team of community health workers to lead local quality improvement efforts.

3. Translating and Disseminating Evidence-based Guidelines for People with Chronic Conditions
Another significant finding for some of the grantees is that evidence-based, disease-specific guidelines are not always fully implemented. Furthermore, they’ve learned that patients often find providers to be minimally responsive to patient care needs. In response, some grantees are providing patients who have chronic conditions with guidelines specific to their disease so that they can be better informed health care consumers and push for greater quality in their own care. A few grantees are also engaging providers in the development of these guidelines, in order to collaborate in more successful dissemination and provider responsiveness.

4. Educating Consumers about Self-care and Self-advocacy
The grantees recognize that lack of support from the health care system for prevention and self-care contributes to poor health for many consumers. This problem is particularly striking for their constituents who are at high risk for health problems or members of linguistically and culturally isolated communities. Such communities often lack relevant and available health education programs and information about health conditions or diseases. In order to address this need, many grantees are educating consumers about prevention and self-care so that they can do more for themselves, thereby reducing preventable and inappro-
Table 2. How the Allies for Quality Define Quality and Their Work to Improve It

<table>
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<tr>
<th>GRANTEE/PROJECT NAME</th>
<th>Types of Quality Problems</th>
<th>Their Work to Improve Quality</th>
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| California Black Health Network: Quality Assurance Project | • Provider assumptions about (lack of) patient compliance in the African American population.  
• Providers’ failure to follow accepted clinical guidelines when treating African American patients.  
• Insensitive treatment for African American patients. | • Assess quality of care issues for African Americans.  
• Inform community members about their rights and responsibilities in the health care system.  
• Raise the awareness of consumers and providers about quality issues through lectures, informational materials, and advocate training. |
• Preventable complications.  
• Patients uninformed about necessary examinations and tests to prevent and reduce complications.  
• Providers uninformed about patient needs.  
• Inability to track and improve upon results.  
• Lack of advice and education, affordable medication, and support for consumers. | • Conduct outreach and education to high-risk communities.  
• Train people with diabetes to be advocates and to provide other patients with evidence-based clinical practice guidelines in the form of the Diabetes Health Record card, which allows a diabetes patient to keep track of the examinations and lab tests they need, their results, and other important diabetes care activities. |
| Center for Disability Issues and the Health Professions: Project to Empower Californians with Disabilities to Seek Quality Care | • Inadequate time with medical professionals.  
• Lack of provider encouragement for consumers to be active participants in their health care.  
• Lack of consumer information to work with medical professionals.  
• Provider lack of familiarity with disability issues and associated medical problems, such as mental health, spinal cord injuries, and congenital birth anomalies. | • Train staff of Independent Living Centers (ILC) around the state to work with clients on quality of care issues.  
• Develop materials for consumers to use in advocating for themselves in the health care system, and distribute to consumers via ILC staff. |
| Community Health Councils, Inc.: Medi-Cal Managed Care Quality Initiative | • Lack of measures that monitor the quality of Medi-Cal managed care, publicly report on that quality, and are relevant and meaningful to consumers’ health care decision-making.  
• Lack of consumer involvement and voice in quality measurement, reporting, and improvement efforts. | • Increase awareness of the quality issues and informational gaps/needs of Medi-Cal managed care consumers among state agencies such as the Department of Health Services, health plans, and consumer advocates.  
• Make recommendations to California agencies on other states’ use of consumer report cards as part of quality assurance efforts.  
• Produce briefs and convene forums to bring attention to these issues and gaps, explore how to address them, and make policy recommendations. |
| Community Health Worker/ Promotoras Network: Improving Quality of Care for Latinos | • Little attention to health care barriers for Latino communities (cultural/linguistic isolation from the health care system, poverty, transportation and child care needs, inflexible service hours for working families).  
• Lack of understanding that survival issues take precedence over preventive health practices and effective utilization of the health care system.  
• Perceived lack of respect from the health care system.  
• Lack of value assigned to CHW/promotoras’ work as community liaisons to the health care system. | • Support the work of CHW/promotoras through a statewide network, leadership development opportunities, and regional trainings on quality of care.  
• Raise awareness around the work that CHW/promotoras do, their value to communities, and the health care system, and their role in identifying local health quality needs and working to improve them.  
• Change institutional practices and policies to expand the health care delivery system to include CHW/promotoras as health system–community liaisons, agents for quality improvement, and voices for community quality needs. |

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appropriate visits to the health care system, particularly the use of emergency rooms. One step toward better quality of care is appropriate use of the health care system.

5. Changing Health Care Delivery Systems
Grantees have found that low-income and uninsured populations often receive substandard care. Some grantees are specifically working to influence the larger health care system, particularly on behalf of underserved populations, by advocating for coordinated and responsive care at the clinical level, for an expanded health care delivery team at the community level, and for greater public accountability for the state agencies and health plans responsible for treating Medicaid patients.

Conclusion
Identifying the roles that consumer and patient organizations are playing to improve health care quality sheds new light on what quality health care may mean to consumers. The consumer and patient organizations that make up the Allies for Quality grantees and their constituents are shaping and framing a broader quality improvement movement that takes into account the consumer perspective. The following conclusions are drawn from their work:

- Many of the quality-of-care issues the Allies for Quality are dealing with concern consumers receiving not only the right care but also respect, equality of treatment, and greater responsiveness from providers.
- Because of their primary focus on consumers, these organizations have often had difficulty getting “seated at the table” to discuss quality improvement issues with institutions such as state health agencies, health plans, and hospitals.

Table 2 (continued from page 4)

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<th>GRANTEE/PROJECT NAME</th>
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| Sickle Cell Disease Foundation of California: Managing My Pain Project | • Racial bias and prejudice affect the quality of care patients receive.  
• Rare disease resulting in limited number of people trained to deal with it.  
• Little social attention and limited funding.  
• Perception of providers that sickle cell disease patients are drug-seeking or drug addicts.  
• Lack of compassion or empathy from physicians. | • Translate clinical pain management guidelines for consumers.  
• Provide sickle cell patients and their families with guidelines about pain management for sickle cell disease and encourage them to advocate for better quality medical care and pain management with health care providers. |
| Women's Health Leadership: Women's Choices Project | • Culturally inappropriate care.  
• Insensitive treatment.  
• Inadequate access.  
• Structural barriers to care. | • Train community leaders in quality health issues, community organizing, and advocacy.  
• Work with each leader to conduct a specific project addressing consumer health quality issues in their communities. |
| Women's Information Network Against Breast Cancer: The Breast Buddy Breast Care Program | • Inadequate explanation of diagnosis and treatment options.  
• In some settings, excessive number of visits and lack of privacy and culturally competent consultation. | • Provide print and video materials to patients immediately following breast cancer diagnosis.  
• Provide consultation to newly diagnosed patients.  
• Train cancer survivors as “breast buddies” to pair with new patients to ensure continued support. |
By building skills and delivering information to consumers, intermediaries, and providers, the Allies for Quality grantees are contributing to the first step of a quality of care movement: empowering consumers. As more intermediary workers (peer educators, outreach workers and staff) and patients involved with the Allies for Quality learn how to advocate for and expect high-quality health care, wider constituencies advocating for greater quality will form.

As the work of the Allies for Quality enables consumers to become educated and skilled at interacting with providers, these consumers will begin to affect how the health care system, as well as how individual providers respond to them and to other patients. Such empowered consumers will create their own path of influence, which, though slow, can be steady even in the face of institutional problems.

Bringing a consumer perspective to health care quality improvement can help to empower consumers and reshape systems to be more responsive to consumer needs. Patient and consumer groups such as those in the Allies for Quality program should continue to be engaged in quality improvement activities and their successes applied in other settings.

Acknowledgments

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About the Project

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Allies for Quality: Patient and Consumer Groups Improving Health Care was developed by the California HealthCare Foundation’s (CHCF) Quality Initiative to support and encourage patient and consumer groups’ involvement in health care quality issues. CHCF is an independent philanthropy committed to improving California’s health care delivery and financing systems. The Quality Initiative is a catalyst for improving the quality and accountability of health care in California through public reporting of performance measures and advancement of improvement and patient safety efforts. More information about the grantees is on the CHCF Web site (www.chcf.org).

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