

# **Patient-Consumer Perspectives on Electronic Health Information Exchange**

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**Redwood MedNet  
Connecting California to  
Improve Patient Care in 2012**  
Rohnert Park, California  
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**ORGANIZATIONS ENDORSING THE  
CONSUMER AND PATIENT PRINCIPLES FOR  
ELECTRONIC HEALTH INFORMATION EXCHANGE IN CALIFORNIA**

*As of October 27, 2010*

Many organizations are working to ensure that electronic health information exchange in California fully incorporates the consumer's and patient's needs and perspectives. These Consumer and Patient Principles are currently endorsed by:

|  |   |   |   |
|--|---|---|---|
| AARP   |    | American Civil Liberties Union of Southern California           |    |
| Asian & Pacific Islander American Health Forum           |    | Association of Asian Pacific Community Health Organizations     |    |
| California Pan-Ethnic Health Network                     |    | California Rural Indian Health Board                            |    |
| Center for Democracy & Technology                        |    | Congress of California Seniors                                  |   |
| Consumer Action  |  | Consumers Union of United States                                |  |
| Family Bridges, Inc.                                     |  | Health Access   |  |
| Latino Coalition for a Healthy California                |  | National Council of La Raza (NCLR)                              |  |
| National Partnership for Women & Families                |  | Pacific Business Group on Health                                |  |
| Planned Parenthood Affiliates of California              |  | Prevention Institute  |  |
| Privacy Activism   |  | Southern Christian Leadership Conference of Greater Los Angeles |  |
| Summit Health Institute for Research and Education, Inc. |  | The Children's Partnership                                      |  |

# **Consumer and Patient Principles for Electronic Health Information Exchange in California**

- 1. Important Benefits for Individual Health.**
- 2. Important Benefits for Population Health.**
- 3. Inclusivity and Equality.**
- 4. Universal Design, Accessibility and Interoperability.**
- 5. Privacy and Security.**
- 6. Preventing Misuse of Health Data.**
- 7. Partnership and HIT Literacy.**
- 8. Accountability.**
- 9. Enforcement.**

# Consumer and Patient Principles for Electronic Health Information Exchange in California

1. **Important Benefits for Individual Health:** Improve individual health care and its quality, safety, and efficiency.
2. **Important Benefits for Population Health:** Improve health for the public and communities at large.
3. **Inclusivity and Equality:** Ensure that all patients and consumers benefit fully and equally.
4. **Universal Design, Accessibility and Interoperability:** Design health information technology and services to meet the range of needs without barriers or diminished function for some, such as people using languages other than English or people with disabilities.
5. **Privacy and Security:** Ensure the privacy and security of patients' health information.
6. **Preventing Misuse of Health Data:** Prevent misuses of health data.
7. **Partnership and HIT Literacy:** Build partnership and HIT literacy among patients, providers, and public health officials.
8. **Accountability:** Hold providers and regulators accountable for realizing the benefits of health information exchange.
9. **Enforcement:** Enforce these principles and protections for patients and communities.

# The State of the State: A Patient-Consumer Perspective

Where do current efforts in  
California stand?

Consumers Union commissioned an independent study by Professor Robert Miller at UCSF to assess how well electronic health information exchange in California is meeting these principles and the needs of California's patients and communities.

First study of its kind; published in *Health Affairs* in March 2012.

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# **Satisfying Patient-Consumer Principles for Health Information Exchange: Evidence from California Case Studies**

## **Methodology:**

- Professor Miller selected five different health care organizations that collectively serve the range of California's different patient populations.
- Each organization is considered a health information technology leader for the patient population it serves.
- The survey occurred between August 2010 and April 2011.

## **Satisfying Patient-Consumer Principles for Health Information Exchange: Evidence from California Case Studies**

### Findings in summary:

- Different organizations had different approaches to, and were at different stages of, health information exchange.
- Three organizations had no patient portal; the other two lacked robust portals meeting some basic patient needs.
- Exchange with affiliated organizations was increasing, but exchange with unaffiliated organizations was negligible.
- No organization's health information exchange initiatives came close to meeting the consumer-patient principles overall.

# What then shall we do?

We must do more strategically and structurally to advance patients' access to and use of their electronic health information.

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## **Satisfying Patient-Consumer Principles for Health Information Exchange: Evidence from California Case Studies**

### **Professor Miller recommended:**

- **Launch public campaigns to increase health information technology literacy for patients;**
- **Set timetables for organizations to offer patient-friendly web-based portals;**
- **Enact rules that enable consumers to easily understand who has accessed their information and correct data; and**
- **Fund and publicize timely evaluations of health information exchange systems and their benefits and risks for patients.**

# But we need a systematic, structural approach.

- We have a Medi-Cal EHR Adoption Incentive Program for physicians and hospitals.
- We need an equivalent EHR Access and Use Program for patients and their caregivers.
- We need a parallel, multi-track approach for doctors and patients together, not a linear approach where patients' needs come later.

# The time is now.

- The HITECH Act calls for “an electronic health record for each person in the United States by 2014.”
- The Department of Health Care Services’ stakeholder vision for EHR adoption in 2009 states:
  - “All patients of Medi-Cal providers with EHRs will have electronic access to their Personal Health Record (PHR) and self-management tools by 2015. Patient tools are affordable, actionable, culturally and linguistically appropriate, and accessible through widely available technologies . . . [and] enable patients to communicate with their providers.”
- The proposed Stage 2 meaningful use criteria would require electronic access, downloading, and transmission for patients.

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