



Achieving the Right Balance: A **Consumer Perspective** on Health Big Data Concerns & Solutions

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Privacy & Security Workgroup
Hearing on Health Big Data
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national partnership
for women & families

About us



The **National Partnership for Women & Families** is a nonprofit, nonpartisan advocacy group dedicated to promoting fairness in the workplace, access to quality health care, and policies that help women and men meet the dual demands of work and family.

The **Consumer Partnership for eHealth** (CPeH) is a coalition led by the National Partnership for Women & Families since 2005 of more than 50 consumer, patient, and labor organizations working at the national, state, and local levels to advance private and secure health information technology (health IT) in ways that measurably improve the lives of individuals and their families.

More information is available at
www.NationalPartnership.org
www.NationalPartnership.org/hit



Recent Conference on Big Data & Civil Rights



- ▶ **Hosted by the Data & Society Research Institute, Leadership Conference on Civil and Human Rights (LCCHR) and New America's Open Technology Institute, on October 30, 2014.**
- ▶ **A broad mix of leaders across the nation discussed big data as a civil rights issue, including **health big data**.**
- ▶ **Two distinct issues were at the forefront:**
 - ▶ **Privacy, and the threat that greater surveillance (big data collection and analysis) poses for low-income communities and communities of color.**
 - ▶ **Health disparities, and the promise of big data to assist population health leaders in identifying, analyzing and addressing health disparities.**

Big Data & Civil Rights (cont.)



▶ **Some broad themes emerged:**

- ▶ The same piece of data can be used to reduce health disparities and empower people, or conversely, to violate privacy and cause harm—depending on who holds the data and what the person does with it.
 - ▶ Greater demographic granularity can help to address health disparities (e.g. identifying someone as “Vietnamese” instead of “Asian”) or increase the risk of profiling.
 - ▶ Information about whether one has had a vaccination could be used for a public education campaign, or for targeting an increase in insurance premiums.
- ▶ All data can be health data, or data from which inferences about health are drawn or correlations with health are made.
- ▶ Focus on uses and harms rather than costs and benefits. Discussing costs and benefits implies trade-offs, and people thought it premature to focus on that calculation. Focusing on harms helps to seek redress through civil rights laws.

Achieving the Right Balance: Health Big Data in a Balanced Consumer Framework



ORGANIZATIONS ENDORSING THE CONSUMER AND PATIENT PRINCIPLES FOR ELECTRONIC HEALTH INFORMATION EXCHANGE IN CALIFORNIA

As of September 7, 2011

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 |  |
| ZeroDivide |  | | |

Patient-Consumer HIE Principles: **Summary**



The nine patient-consumer principles address:

1. Benefits for **personal** health
2. Benefits for **population** health
3. Ensuring that all patients and consumers benefit fully and equally
4. Designing the technology and services to meet the range of needs without barriers or diminished function for some communities
5. Ensuring the **privacy and security** of patients' health information
6. Preventing **misuse** of patients' data
7. Building partnership and HIT literacy among patients, providers, and public health officials
8. Accountability for achieving the benefits of health information exchange
9. Enforcing these protections for patients and communities

For more information



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