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# Discrimination and Compelled Disclosures

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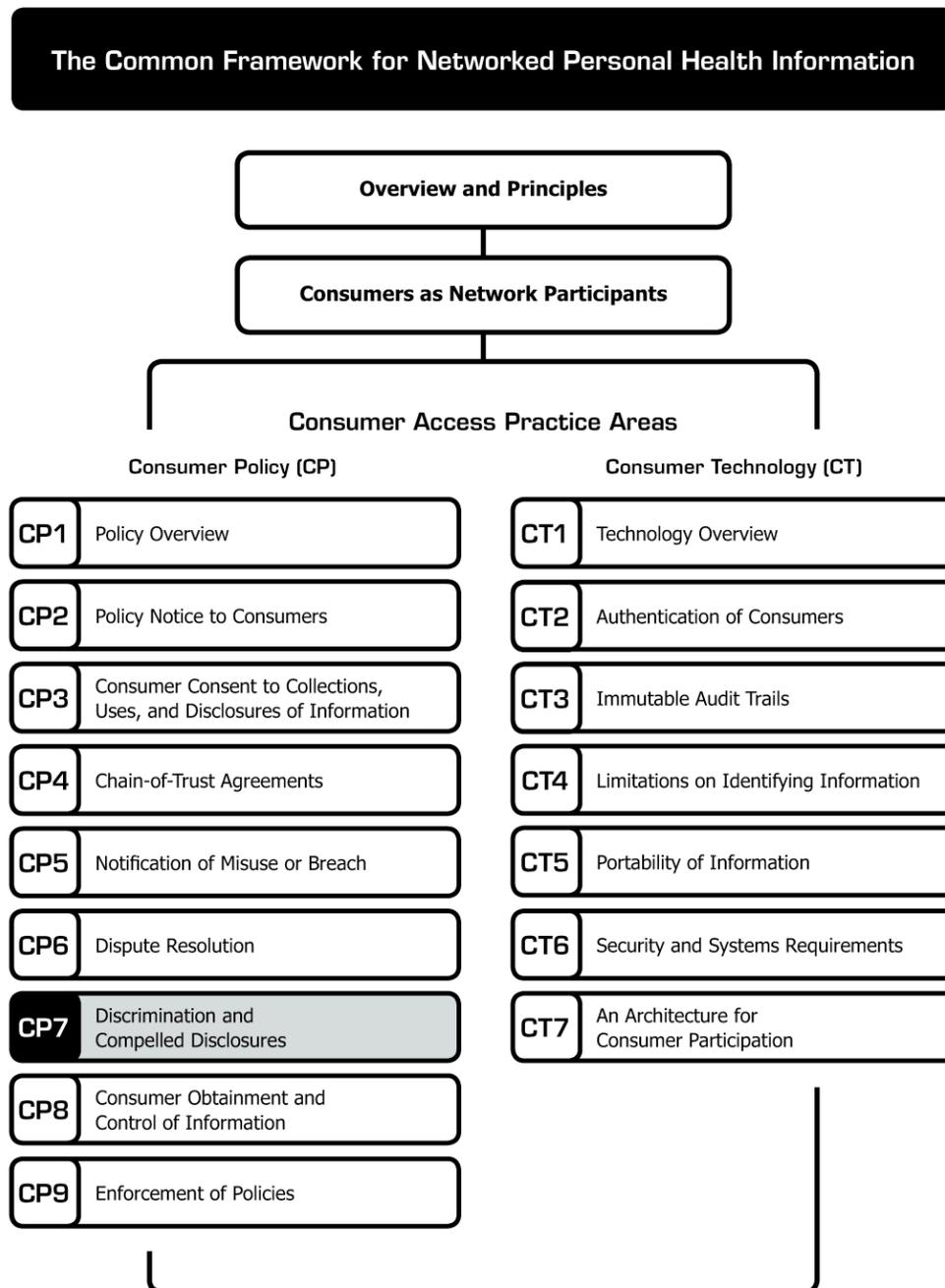
# **Discrimination and Compelled Disclosures**

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The document you are reading is part of the **Connecting for Health Common Framework for Networked Personal Health Information**, which is available in full and in its most current version at <http://www.connectingforhealth.org/>.

This framework proposes a set of practices that, when taken together, encourage appropriate handling of personal health information as it flows to and from personal health records (PHRs) and similar applications or supporting services.

As of June 2008, the Common Framework included the following published components:



## Discrimination and Compelled Disclosures \*

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**Purpose:** Recent **Connecting for Health** public opinion research found that more than half of respondents were “very concerned” that employers or health plans would gain access to electronic information intended for PHRs.<sup>1</sup> Worry about possible employment or insurance discrimination likely drives these high numbers.

**CT1: Technical Overview** discusses “business data streams” and “consumer data streams.” Business data streams consist of transactions of personal health information among business partners conducted without a consumer view or participation. For example, consumers generally don’t see the transactions between their doctor’s office and the insurance company, or between the insurance company and its data warehouse, etc. Consumer data streams involve transactions of information into or out of a consumer-accessible application, such as a PHR.

In addition to the enforcement of existing anti-discrimination laws, any organization acting as Consumer Access Service or PHR supplier should maintain a “firewall” between consumer data streams and business data streams to ensure that data captured or stored in consumer applications are not used as a basis for discrimination.

Our Work Group recommends that all network participants treat consumer data streams distinctly — with higher levels of

*This practice area speaks to a need to develop **sustainable consumer trust** in consumer data streams.*

protection than existing business streams of health data. This practice area recommends tough language to bar discrimination or “compelled disclosures” — such as when the consumer’s authorization for release of data is required in order to obtain employment, benefits, or other services.

### Discrimination

It is important to recognize that consumer data streams and networked PHRs may lead to a commingling or at least co-existence of data from a variety of sources, including the consumer. It would threaten the consumer’s trust in the entire network if the PHR were used as the source of information, no matter its origin, that affected an underwriting or employment decision. The **Connecting for Health** Common Framework policies for health information exchanges prohibit use of information for discriminatory purposes.<sup>2</sup> Similarly, employer groups have publicly stated that they will never access individually identifiable information generated and stored in the PHR services that they offer to their employees.

#### *Recommended Practice:*

The preferred practice is to guarantee that none of the information made accessible to or from the consumer’s application — that is, none of the consumer data stream — can ever be used to discriminate against consumers. In addition to complying with all anti-discrimination laws and regulations, all entities that access information in a consumer data stream should make public statements, and develop internal practices

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\* **Connecting for Health** thanks Josh Lemieux, Markle Foundation, for drafting this paper.

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<sup>1</sup> Lake Research Partners and American Viewpoint, commissioned by **Connecting for Health**. *Survey Finds Americans Want Electronic Personal Health Information to Improve Own Health Care*. December 2006. Available online at the following URL: [http://www.markle.org/downloadable\\_assets/research\\_doc\\_120706.pdf](http://www.markle.org/downloadable_assets/research_doc_120706.pdf).

<sup>2</sup> **Connecting for Health** Common Framework, *Model Privacy Policies and Procedures for Health Information Exchange*. June 2006, p. 10-11. Available online at: [http://www.connectingforhealth.org/commonframework/docs/P2\\_Model\\_PrivPol.pdf](http://www.connectingforhealth.org/commonframework/docs/P2_Model_PrivPol.pdf).

against using information in consumer data streams for purposes of discrimination. When appropriate, Consumer Access Services and PHRs should include anti-discrimination clauses in their contracts with partners. The best means of preventing information from being used for discrimination is to put in place strong policies and access control procedures.

It is noted that some organizations, particularly HIPAA-Covered Entities such as health plans and self-insured employers, collect personal health information to perform their business operations (i.e., as part of the business data stream) as well as offer Consumer Access Services. In addition to complying with all anti-discrimination laws and regulations, such organizations should use prudent practices such as implementing a “firewall” between consumer data streams and business data streams in order to prevent even the appearance of being able to use information in consumer data streams for purposes of discrimination.

### **Compelled Disclosures**

According to the chair of the Subcommittee on Privacy and Confidentiality of the National Committee on Vital and Health Statistics: “Each year, as a condition of applying for employment, insurance, loans, and other programs, millions of individuals are compelled to sign authorizations permitting employers, insurers, banks, and others to access their personal health information for non-medical purposes. These authorizations are nominally voluntary; individuals are not required to sign them, but if they do not, they will not be considered for the particular job, insurance policy, loan, or benefit. In addition, for most of these authorizations, no limits are placed on the scope of the information disclosed or the duration of the authorization.”<sup>3</sup>

Few laws or regulations place limits on such compelled disclosures. To date, most information released under such circumstances

comes from what we call business data streams, e.g., from official medical records, etc.

If consumer data streams and PHRs are opened to such compelled authorizations, it will seriously undermine the public confidence in these new tools. If consumers fear that information in their networked PHR must be released to third parties considering their applications for employment, benefits, loans, etc., many will avoid health information services that might otherwise help them manage their health.

#### *Recommended Practice:*

Absent statutory protection from compelled disclosures, the emerging industry of Consumer Access Services should take a strong public and legal stand against third parties seeking to make their own access to consumer data streams and networked PHR information a condition of an individual’s employment, benefits, or other services important to the well-being of individuals.

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<sup>3</sup> Rothstein, Mark, June 2006 Letter to HHS Secretary Leavitt. Accessed online on October 9, 2007, at the following URL: <http://www.ncvhs.hhs.gov/060622lt.htm>. See also *Compelled Disclosure of Health Information: Protecting Against the Greatest Potential Threat to Privacy*. JAMA, Volume 295(24), 28 June 2006, p. 2882-2885.

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## Connecting for Health Work Group on Consumer Access Policies for Networked Personal Health Information

### Lead

**David Lansky**, PhD, Pacific Business Group on Health (Chair)

### Staff

**Matt Kavanagh**, Independent Contractor  
**Josh Lemieux**, Markle Foundation

### Members

**Wendy Angst**, MHA, CapMed, A Division of Bio-Imaging Technologies, Inc.

**Annette Bar-Cohen**, MPH, National Breast Cancer Coalition

**Jeremy Coote**, InterComponentWare, Inc.

**Maureen Costello**, Ingenix

**Diane Davies**, MD, University of Minnesota

**James Dempsey**, JD, Center for Democracy and Technology

**Stephen Downs**, SM, Robert Wood Johnson Foundation

**Joyce Dubow**, AARP

**Thomas Eberle**, MD, Intel Corporation and Dossia

**Lisa Fenichel**, Health Care For All

**Stefanie Fenton**, Intuit, Inc.

**Steven Findlay**, Consumers Union

**Mark Frisse**, MD, MBA, MSc, Vanderbilt Center for Better Health

**Gilles Frydman**, Association of Cancer Online Resources (ACOR.org)

**Melissa Goldstein**, JD, School of Public Health and Health Services Department of Health Sciences, The George Washington University Medical Center

**Philip T. Hagen**, MD, Mayo Clinic Health Solutions

**Robert Heyl**, Aetna, Inc.

**David Kibbe**, MD, MBA, American Academy of Family Physicians

**Jerry Lin**, Google Health

**Kathleen Mahan**, MBA, SureScripts

**Ken Majkowski**, PharmD, RxHub, LLC

**Philip Marshall** MD, MPH, WebMD Health

**Deven McGraw**, Center for Democracy and Technology

**Kim Nazi\***, FACHE, U.S. Department of Veterans Affairs

**Lee Partridge**, National Partnership for Women and Families

**George Peredy**, MD, Kaiser Permanente HealthConnect

**Joy Pritts**, JD, Center on Medical Record Rights and Privacy, Health Policy Institute, Georgetown University

**Scott Robertson**, PharmD, Kaiser Permanente

**Daniel Sands**, MD, MPH, Cisco Systems, Inc.

**Clay Shirky**, New York University Graduate Interactive Telecommunications Program

**Joel Slackman**, BlueCross BlueShield Association

**Anna Slomovic**, PhD, Revolution Health

**Cynthia Solomon**, Follow Me

**Ramesh Srinivasan**, MedicAlert Foundation International

**Michael Stokes**, Microsoft Corporation

**Susan Stuard**, New York-Presbyterian Hospital

**Paul Tang**, MD, Palo Alto Medical Foundation/Sutter Health

**Jeanette Thornton**, America's Health Insurance Plans

**Frank Torres**, JD, Microsoft Corporation

**Tony Trenkle\***, Centers for Medicare & Medicaid Services

**Jonathan Wald**, MD, Partners HealthCare System

**James Walker**, MD, FACP, Geisinger Health System

**Marcy Wilder**, JD, Hogan & Hartson LLP

**Anna Wong**, Medco Health Solutions, Inc.

**Matthew Wynia**, MD, MPH, CAPH, American Medical Association

**Teresa Zayas-Caban**, PhD\*, Agency for Healthcare Research and Quality

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