

The logo for the Health Privacy Project, featuring the words "HEALTH", "PRIVACY", and "PROJECT" stacked vertically in white, uppercase, sans-serif font within a solid purple square.

## HEALTH PRIVACY PROJECT

### **Best Practices for Employers Offering Personal Health Records (PHRs) Released Today**

December 19, 2007 —

Today the Health Privacy Project, the California HealthCare Foundation, and a group of corporate leaders release **Best Practices for Employers Offering Personal Health Records (PHRs)**. While a number of companies already are offering PHRs, concerns about consumer anxiety and regulatory uncertainty persist. The ten Best Practices are designed to address these concerns. Highlights include that employers should give employees control of access to and use of the PHR, and the establishment of “chain of trust” agreements between employers and their business partners to assure that information in the PHR is consistently protected.

Over the past year, the *Employers’ Working Group on PHRs*, convened by the California HealthCare Foundation and IBM, developed these Best Practices through a collaborative process. The Best Practices are intended to serve as aspirational guidelines for employers, not a one size fits all solution, as companies develop and implement their own PHR-related policies and practices.

Sam Karp, Vice President of Programs at the California HealthCare Foundation said, “These Best Practices address a void in policy and practice guidelines for employers.” The Foundation’s 2005 national consumer survey on health privacy, which prompted the convening of this group, found increasing consumer concern about the potential for employer misuse of their personal health data. “The Best Practices are a significant step toward addressing these concerns,” Karp added.

The Best Practices closely follow the release of an employee survey by the National Business Group on Health, a nonprofit membership organization including 65 of the Fortune 100. Its President, Helen Darling, said, “We know that employees and their dependents care deeply about the privacy and confidentiality of their personal health records (PHRs). Employers will want to follow these excellent, thoughtful guidelines to reassure their employees that their information will be safe.” The survey shows that the

vast majority of employees, if offered a PHR by their employers, wants to decide what information it contains and who has access to it. Most strikingly, 85% said it was important or extremely important that their privacy be protected and that employers be prohibited from accessing the PHR.

“The Best Practices will go a long way toward helping employers establish the trust of their employees—everybody benefits,” said Janlori Goldman, Director of the Health Privacy Project, which staffed the initiative.

Harriet Pearson, Chief Privacy Officer at IBM, who helped organize the employer working group, said, “IBM has a longstanding record of commitment to protect employees’ privacy. We are delighted to be part of this effort and believe it will foster trust in PHRs and help employees to better manage their healthcare.”

Zoe Strickland, Vice President and Chief Privacy Officer at Wal-Mart, and a member of the group, added, “The Best Practices for Employers Offering PHRs is a key step to ensuring that employees have control over their information. These Best Practices contain important guidelines for employers to use in developing new policies or evaluating existing policies regarding personal health records.”

*Members of the Employers’ Working Group on PHRs* include representatives from the following companies and organizations:

**Center for Democracy & Technology, Dell, Google, Hewitt Associates, IBM, Markle Foundation, Omnimedix Institute, Pfizer, Pitney Bowes, Revolution Health, Wal-Mart, and WebMD.**

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## **Best Practices for Employers Offering Personal Health Records (PHRs)**

### **1. Transparency and Notice**

Employers should be transparent about their reasons for offering a PHR to employees and all policies that apply to the PHR. Employers should provide an Information Policy Statement or Notice that clearly lays out the ways in which information in the PHR will be used and safeguarded. Employers should incorporate the Notice into their health benefit programs, and should make it available in a layered format—a short concise version to accompany a more detailed one. Employees should be informed of any updates to the policy.

### **2. Education**

Employees should be educated about the benefits, functions, and content of the PHR. Information about the PHR should be communicated in numerous ways to build both knowledge and trust.

### **3. Employees Can Choose which Content is Included in the PHR**

Employees should be able to determine the content of the PHR, including which providers and plans contribute to it. Employees should be able to annotate the records submitted by others, as well as to enter their own information, with employee-entered data marked as such. The identification of sources of all personal health information in the PHR should be readily apparent.

### **4. Employees Control Access to and Use of the PHR**

- a.) Employees should control who is allowed to access their PHRs. Employers should not access or use employees' individually-identifiable health information from the PHR.
- b.) Employees should choose, without condition, whether to grant access to personal health information within their PHRs for any "secondary uses". An audit trail that shows who has accessed the PHR should be easily available to employees.

### **5. Employees Can Designate Proxies to Act on their Behalf**

Employees should determine who, including family members and caregivers, should have direct access to their PHRs on their behalf. Where possible, employees should be able to grant proxy access to full or partial information in their PHRs, including access in emergency circumstances. Employees should also have the ability to revoke access privileges.

### **6. "Chain of Trust": Information Policies Extend to Business Partners**

The information policies and practices of employer-sponsored PHRs should follow the data through chain of trust agreements that require business partners to adhere to the employer's applicable policies and practices.

## **7. Data Security**

Employers should provide a strong level of security to safeguard the information in the PHR systems. A robust authentication process for access to PHRs should be required, in addition to an audit trail that shows who has accessed information and when.

## **8. Data Management**

Employers should ensure that the PHR systems they provide have comprehensive data management strategies that protect the integrity of the data and include data retention policies.

## **9. Enforcement and Remedies**

Employers should establish oversight and accountability mechanisms for adhering to their PHR policies and practices. Employers should put into place a mechanism to promptly notify employees of any inappropriate access to or use of information contained in an employee's PHR, identify the steps which have been taken to address the inappropriate activity, and make resources available to employees to assist them in addressing the effects of the inappropriate activity.

## **10. Portability**

Employers should offer PHRs that are portable, to the extent feasible, allowing employees to maintain or move the PHR and/or the data it contains even after employment or coverage ends or changes.

The Best Practices and a background paper about them are also available at [www.healthprivacy.org/bestpractices](http://www.healthprivacy.org/bestpractices).

Lygeia Ricciardi of Clear Voice Consulting, LLC provided consulting services for this initiative.