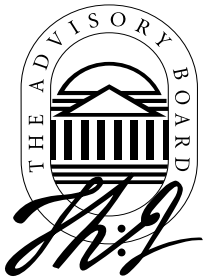


Strategies for Addressing Privacy and Ethical Concerns Associated with Sharing Health Information

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RESEARCH IN BRIEF

Employers, including health system administrators, often collect employee health information through health risk assessments (HRAs). The goals of these assessments are to simultaneously reduce health care costs for the employers while ensuring that individuals at high risk for certain conditions are identified and assisted in accessing appropriate health care. With the advent of electronic medical records (EMRs), the sharing of such health information will be easier and may reap such benefits as improved quality of care. However, employees may object to the sharing of such information, for fear of discrimination and stigmatization by their employers. This brief provides an overview of the ethical and privacy concerns associated with the sharing of health information as handled by four health systems.

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MAJOR SECTIONS

- I. Introduction and Observations
- II. Profile: *HRA information shared with health plan, PCPs*
- III. Profile: *Cover letter sent with HRA to reassure employees about privacy concerns*
- IV. Profile: *Fifty percent of staff participate in HRA*
- V. Profile: *Third-party contractor maintains sole access to employee health information*

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I. INTRODUCTION AND OBSERVATIONS

The increased use of electronic medical records (EMRs) offers health care professionals the opportunity to exchange patient health information among disparate clinicians and other entities, such as insurers, in electronic form. Sharing patient health information in this manner includes many benefits for patients, chiefly that they may receive an improved continuum of care as their providers will have ready access to their complete clinical histories.¹ Additionally, the sharing of digitally-stored health information across an individual's lifetime—albeit with appropriate personnel—may have substantial benefits for health care education and research.²

Employees may fear discrimination and stigmatization if they share health information

Regardless of such benefits, many privacy and ethical concerns are associated with the collection and sharing of health information. This issue is particularly sensitive when the health information belongs to the institution that will collect and store the data as employees may fear discrimination or being stigmatized as a result of their health conditions.³

While 50 to 70 percent of Americans support sharing health information, 91 percent express privacy concerns

Overall, research indicates that Americans are ambivalent about EMRs and the prospective sharing of health information therein. A 2003 survey suggested that between 50 and 70 percent of Americans believed that having their personal health records online would positively affect their health care, with the highest among those already using e-health services or suffering from a chronic illness.⁴ Respondents to the survey were most comfortable with physicians accessing their medical records online, with 79 percent supporting such availability.⁵ In contrast, only 23 percent of respondents were comfortable with insurers having access to their health records.⁶ Regardless of varying levels of comfort with regards to medical record access, a full 91 percent expressed some level of privacy or security concern regarding online medical records in general.⁷

Health system administrators have thus had to review such service offerings as health risk assessments (HRAs), which involve the collection of health information from employees that is at once sensitive and potentially important to share among providers.⁸ Most continue to offer HRAs despite such concerns in an effort to reduce insurance costs and improve employee health by identifying high-risk individuals and facilitating their enrollment in appropriate disease management programs. However, they meanwhile navigate the complicated privacy and ethical concerns that may arise.

The observations listed on the following page were drawn from interviews with four administrators at health systems that collect health information through HRAs and have successfully navigated such issues.

¹ "Software Project Builds Interoperability into Medical Information Systems." *Science Letter*. (January 24, 2006).

² *ibid.*

³ Advisory Board interview, (April 2006).

⁴ Westin, A, et al. "Building Privacy by Design in Health Data Systems." Center for Social and Legal Research. (August 2005). www.pandab.org/EHRRept9-6-05.pdf (Accessed April 25, 2006).

⁵ *ibid.*

⁶ *ibid.*

⁷ Westin, A, et al. "Building Privacy by Design in Health Data Systems." Center for Social and Legal Research. (August 2005). www.pandab.org/EHRRept9-6-05.pdf (Accessed April 25, 2006).

⁸ Advisory Board interview, (April 2006).

Observation #1—Employee concerns with sharing health information may include discrimination and stigma associated with certain health-related issues.

None of the interviewed administrators recalled any significant problems arising as a result of the collection or sharing of employee health information within their health system. However, with regards to HRAs, each indicated that employees occasionally asked questions regarding the use of the system, implying that they may be concerned about possible discrimination or stigmatization. In particular, administrators speculate that employees are concerned about discrimination with regards to benefits, insurance premiums, and employment should their employer or insurance company obtain health information that indicates they have or are at high risk for certain conditions. Additionally, employees may be concerned or embarrassed about certain conditions—particularly those related to psychological disorders, sexual health, and substance abuse—that are often associated with stigmas.

Observation #2—Explicit explanation of HRA, information access, and use are often effective in allaying employee privacy concerns.

Providing explicit information regarding the use of the health information and detailing who—be that administrators or providers—will have access to this information often allays most employee concerns. Transparency in health information collection and access serves to reassure employees of the appropriate use of the information they provide.

Observation #3—Educating employees on the meaning and significance of HIPAA provides reassurance of appropriate use of health information within the health system.

Employees who are adequately educated about the significance of Health Information Portability and Accountability Act (HIPAA) and feel secure in their organization's compliance with its standards may express fewer concerns about the collection and sharing of health information. For example, the administrator at the hospital profiled in Section II offers an HRA to health system employees and subsequently shares this information with the system's health plan and relevant PCPs. However, employees have expressed minimal concerns regarding privacy or ethical issues. Administrators attribute this trust to the substantive education provided employees regarding HIPAA compliance, which effectively reassures them about potential for abuse of their health information.

Observation #4—Sharing information with health insurers and PCPs eliminates testing redundancy, may improve patient care.

Administrators likewise find that, though sharing health information may raise certain privacy concerns, it has benefits for patients as well as employers. In particular, the sharing of this information reduces the need for redundant testing, guarantees that insurers are aware of patient compliance with disease management requirements, and improves the continuum of care for a patient by providing relevant test results to PCPs. Administrators suggest that emphasizing these points to employees may reduce objections as employees will appreciate the utility and efficiency of such data sharing.

Observation #5—Use of third-party contractor to dissociate health system from collection and use of health information also helps to eliminate most privacy concerns.

Those administrators who wish to avoid implication in the collection and sharing of health information often enlist third-party contractors to administer HRAs, analyze results, and even follow-up with patients thereafter. This strategy effectively eliminates many privacy concerns; however, administrators note that it may reduce leverage in encouraging employees to enroll in disease management programs. Likewise, it prevents information-sharing with other providers, which may have substantial benefits for employers and employees alike in the form of cost reductions and improved health care quality.

II. PROFILE: *HRA information shared with health plan, PCPs*

Since 2000, health system administrators have offered HRAs to their employees that are both voluntary and self-reported. While participation has been relatively high for such a program—with as many as 40 percent of employees taking an HRA—administrators have implemented some changes that will go into effect for the HRA administered in August 2006. In particular, administrators have decided to have employees submit the HRA online and to keep electronic records of the assessments to facilitate improved sharing with the providing health plan. Prior to making this change, administrators held meetings to discuss potential ethical and privacy concerns that might arise. However, they continue to expect these concerns to be minimal as a result of transparency and strong employee education efforts with regards to HIPAA—an effort that works to reassure employees of the safety of sharing health information and its appropriate use thereafter.

Health system staff provides HRAs, incentives based on meeting criteria on six measures

HRAs are currently provided in two forums, including via mail and at health fairs where community members can receive an assessment in addition to health system employees. In both cases, participation is voluntary and the tests are largely self-administered, though nurses and wellness office staff are available to assist patients at the health fair. The HRA provided through the health fair is generally considered to be more accurate than the purely self-administered one sent home as nurses can test patients' blood pressure at the site and take a blood sample to send to the lab for blood sugar and cholesterol readings.

All scoring is likewise performed by the staff of the wellness center. Staff members manually score the assessments, providing employees with a pass or fail score for six health criteria. These scores are subsequently used to determine whether a participant is eligible for an incentive, which typically consists of rebates from the health system's health insurance company. Administrators note that these incentives are a primary reason for their relatively high participation rate.

Institution type:	500-bed, two-hospital, not-for-profit health system located in the East
Source:	VP, human resources (HR)
HRA characteristics:	<ul style="list-style-type: none"> • Distributed and assessed by wellness office • Soon to be offered electronically • Will be shared with self-insured health plan's TPA and employees' PCPs once information is collected online
Ethical and privacy concerns:	<ul style="list-style-type: none"> • Discrimination with regards to benefits and employment status
Strategies to mitigate concerns:	<ul style="list-style-type: none"> • Administrators/employers receive a summary report • Strong HIPAA education • Voluntary participation

HRAs to be offered online in 2006 to improve sharing with health plan and PCPs

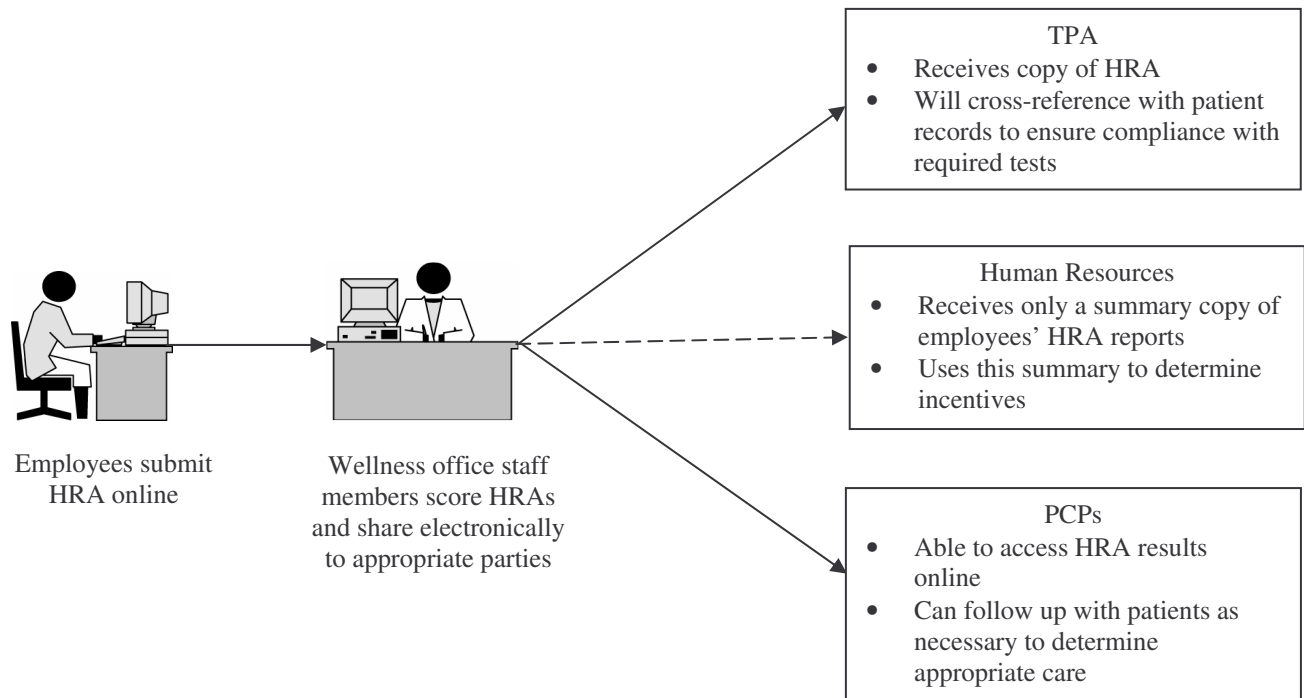
Administrators recently decided to begin offering their HRAs online. This decision was made in part to make taking the HRA easier on employees and scoring easier for staff members in the wellness department. The primary goal of the HRA is to reduce health insurance premiums by increasing enrollment in disease management programs for high-risk employees. Thus, administrators felt that it was important to share the results of the HRAs as follows to improve the quality of care provided to high-risk employees:

- ❖ **PCPs**—Administrators in the wellness center plan on electronically sharing health information collected through an HRA with the employees' PCPs. The information would be delivered to the PCP designated by the employee taking the HRA electronically. The goal is to facilitate that employee's enrollment in an appropriate disease management program thereafter and thus ensure a better continuity of care. Likewise, providing physicians with these results ensures that they will not require their patients to re-take tests that have already been performed recently.
- ❖ **TPA/Health plan**—The health plan provided by the health system requires that patients with certain chronic illnesses—such as diabetes or high cholesterol—regularly receive testing. Providing an HRA often complicates this for high-risk employees because, though they will receive the required testing when taking an HRA, this information is often not shared with the health plan. Thus, employees may be categorized as “non-compliant” by the health plan when in fact they received appropriate testing. Sharing health information and test results provided through an HRA mitigates this issue and reduces the burden placed on employees to ensure that the health plan has the information or to schedule appointments to have a second and thus redundant round of testing performed.

While information from HRAs will be shared with the health plan and relevant PCPs, administrators in HR and other offices have limited access to the results of HRAs, receiving only an overview that a particular employee meets certain health criteria but are at high-risk in other, relatively general categories. The graphic on the following page provides an overview of how HRA results will be shared by this health system.

Patient HRA reports shared with TPA and PCPs electronically

Electronic sharing of health information, 2006



Source: Advisory Board interview, April 2006.

Employees express minimal concern about privacy due to strong HIPAA education

At first, administrators worried that sharing information outside the wellness center—specifically with insurers and PCPs—would raise privacy concerns among participating employees, but they have as yet not experienced any significant problems. Most employees have expressed appreciation for the improved coordination that will result from the electronic sharing of results with insurers and PCPs. Likewise, those few questions that have arisen with regards to privacy—primarily whether it will have any bearing on their employment or benefits status—have been easily allayed.

Administrators attribute the limited concern and ease in reassuring employees about the privacy and appropriate use of their health information to the fact that they have provided them with strong education on HIPAA. Employees in their health system understand HIPAA restrictions and recognize that it protects them from discrimination and the inappropriate sharing of their health information. Thus, when they are informed that their HRAs are HIPAA-compliant, they feel reassured that participation is to their benefit and will not have negative consequences for them in the future.

III. PROFILE: *Cover letter sent with HRA to reassure employees about privacy concerns*

Administrators of the health system have provided HRAs to their employees intermittently since 1995 and are planning to reinstate a larger program in 2007 as a regular offering. Out of concern that employees of the health system would react negatively to having their health information collected mandatorily, administrators have always and plan to continue to offer HRAs on a voluntary basis. However, administrators have found that operating a voluntary program has many detriments—in particular, limiting the scope of the HRA and thus preventing administrators from identifying many high-risk employees—though it has eliminated any possible protests regarding associated privacy and ethical issues.

Employees fear discrimination and stigma with regards to health issues

When health system administrators were developing an HRA offering, their primary goal was to ensure that high-risk employees receive necessary medical attention early, ultimately reducing insurance costs for the health system as a whole. However, they recognized that ethical and privacy concerns may be an issue and thus held a series of meetings to discuss the best way to approach HRAs. In particular, health system administrators acknowledged that employees might be unwilling to participate in an HRA operated by their employer for fear that the information may be used in a discriminatory fashion if they should be identified as being at high risk for certain health problems. Health-related discrimination might include the following:

- ❖ Benefits
- ❖ Employment status (i.e.—the possibility of being laid-off)
- ❖ Insurance (particularly with regards to co-pays)
- ❖ Promotions

In addition to fearing discrimination related to health issues, employees also may object to sharing health information due to associated stigmas or general embarrassment. Health issues about which employees are particularly concerned about either discrimination or stigma include those listed on the following page.

Institution type:	900-bed, two-hospital, not-for-profit teaching health system located in the East
Source:	Director, employee health services
HRA characteristics:	<ul style="list-style-type: none"> • Distributed and assessed by third-party vendor • Mailed to employee homes, submitted in hard copy, and analyzed by third party • Nurse will soon collect biometrics and other health information directly at employee health fairs • Participation is voluntary and currently self-reported • Summary report available to employee health administrators
Ethical and privacy concerns:	<ul style="list-style-type: none"> • Discrimination resulting from insurer or employer knowledge of health problems • Stigma associated with certain health problems
Strategies to mitigate concerns:	<ul style="list-style-type: none"> • Administrators/employers receive only a summary report • Third-party vendor assesses HRAs • Voluntary participation

- Depression and other mental illnesses
- Gynecological (GYN)-related problems for women
- Infectious diseases (such as HIV/AIDS)
- Prostate and sexual health-related issues for men
- Substance abuse

In contrast, people are often less sensitive or reluctant to share information pertaining to weight and blood pressure-related problems. Administrators speculate the employees are more forthcoming with regards to obesity-related health problems because they are visible issues and thus difficult to keep private.

Voluntary HRAs mailed to employees' home addresses, reviewed by third party

Administrators decided that it was important to make participation in the HRA voluntary as they were concerned that mandatory participation might be perceived as overly invasive and as a violation of employees' privacy rights. Likewise, administrators determined that it was important that the HRA be operated by a third party so as to dissociate the health system's administration from the review and appraisal process.

Cover letter reassures employees with regards to privacy concerns

Employees were reassured of the innocuous nature of the HRA through a cover letter that was sent to their homes along with the form. This cover letter highlights the points detailed below:

Cover letter reassures employees with regards to privacy concerns

Content of cover letter accompanying an HRA, 2006

- A third-party vendor would be reviewing and assessing the survey
- Administrators would receive a summary report such that individual results would remain private
- Results would be scored by a software system
- Voluntary nature of the HRA

Source: Advisory Board interview, April 2006.

Administrators felt that such transparency of the risk assessment process would effectively allay employee concerns with regards to privacy issues.

Detriments of voluntary HRAs include low return rates and self-selected participants

While providing HRAs on a voluntary, self-reporting basis successfully mitigates ethical and privacy concerns among employees, administrators note several disadvantages to this model. In particular, they maintain that self-reported statistics are often inaccurate as people often estimate or falsely report their biometrics. As a result, self-reporting fundamentally undermines the mission of an HRA, which is to identify high-risk employees such that they can receive the medical attention they need.

Likewise, administrators note that voluntary reporting results in a self-selected audience. Although allowing participants to opt to take an HRA mitigates ethical and privacy concerns—since those who are concerned with this issue can self-select not to participate—self-selection also limits the scope and effectiveness of an HRA and its impact in improving employee health and reducing insurance costs. For example, only 30 percent of health system employees participated in the HRA offered in 2000.

Administrators revise HRA program but maintain voluntary participation

Unwilling to implement a mandatory HRA program for fear of raising ethical and privacy concerns among employees, administrators have chosen to revise the manner in which they provided HRAs and collected health-related information from employees. In the past, HRA surveys have been mailed to the homes of employees to be submitted via mail to a third-party provider. However, in acknowledgement of the inaccuracy of self-reported health statistics, administrators have decided to have nurses run HRAs and collect relevant health information at organization-run health fairs in the future.

Additionally, administrators are considering expanding the focus of voluntary HRAs to include health-related issues other than those related to obesity, hypertension, and smoking—the three most common focuses of HRAs. In particular, they would like to include questions in their new HRAs related to mental health problems, since psychiatric issues such as depression and anxiety can often result in problems in the workplace and high medical costs in the long term. They are weighing the issue with regards to the potential benefit and the potential decline in participation due to the lengthened and personal nature of an HRA covering such issues. Decisions pertaining to the focus of an HRA and its content must be considered by leaders of each organization from both a practical and a philosophical standpoint based on the perceived needs of employees.

IV. PROFILE: *Fifty percent of staff participate in HRA*

Since 1993, administrators have offered an integrated employee health program to the staff members of their health system. The program includes the provision of a comprehensive HRA by a third-party contractor and follow-up by the health system’s case management and employee wellness departments should an employee be deemed at high risk. Although certain hospital administrators have access to the results of the HRA, the health system has never experienced substantial opposition or received complaints from employees about the HRAs on ethical or privacy grounds—a fact administrators attribute to the voluntary nature of the offering and the limited availability of the results.

Third-party contractor collaborates with staff to provide HRAs, analyzes them electronically

In an effort to dissociate health system administrators from the collection, analysis, and subsequent use of the health information collected through an HRA, administrators decided to employ a third-party contractor. This contractor is responsible for overseeing the administration of the HRA, analyzing its results, and developing a profile of each employee from the results. However, though overseen primarily by this contractor, health system staff members are actively involved in both the administration of the HRA and in following up with employees deemed to be at high risk for certain health problems. In particular, health system nurses collect some of the health information during an HRA—particularly biometrics such as blood pressure and weight to avoid inaccurate or false reporting—and will follow up with employees directly once the contractor has developed an analysis of their health. Nurses use an electronic software program to collect this information and submit it to the contractor, who then assumes responsibility for analyzing the data electronically.

Institution type:	600-bed, three-hospital, not-for-profit health system located in the East
Source:	Administrative director, employee wellness services
HRA characteristics:	<ul style="list-style-type: none"> • Employee wellness office follows up with high-risk employees • Incentives provided for participation • Information collected and analyzed electronically • Third-party contractor conducts HRAs
Ethical and privacy concerns:	<ul style="list-style-type: none"> • Sharing of information with HR such that it could affect benefits or employment
Strategies to mitigate concerns:	<ul style="list-style-type: none"> • Use of third-party contractor dissociates health system from analysis and use of information

Voluntary nature of HRAs reduces objections; incentives improve participation rates

Currently, the HRA is purely voluntary. Nevertheless, participation is relatively high, with approximately 50 percent of employees participating. Administrators attribute this high voluntary participation rate to the fact that they offer incentives for HRAs and—more specifically—for adopting healthier habits thereafter. Providing incentives regarding the adoption of healthy habits speaks to the stated objective of the HRA program—to facilitate employees becoming involved in disease management programs. Administrators focus much of their advertising for HRAs on highlighting these incentives, detailing to employees that incentives for participation include the items listed on the following page.

- ❖ Cash
- ❖ Extra leave days
- ❖ Rebates on health insurance payments

Transparency of information use allays concerns

Although administrators advertise open enrollment for HRAs mostly through fliers and e-mail notices, they note that word-of-mouth advertisement likely attracts the most participants and is largely responsible for allaying many privacy concerns. Each year, nurses administering the HRAs are taught to outline all details of confidentiality of this information to participating employees. These nurses ensure that each participant knows exactly who will see the data and that a contractor—rather than health system administrators—will be scoring the results, which will then be sent to their homes confidentially. They also tell participants that the employee wellness office will receive profiles of those at high risk for certain health problems such that they can assist those employees in entering the appropriate disease management program. Administrators speculate that participating employees relay this confidentiality information to their co-workers such that most concerns are already allayed by the time new participants take an HRA the following year.

Primary concerns focus on sharing of information with HR

Although administrators have not had an employee voice substantial concern about the nature or use of health information, they note that questions have been asked in the past. Primarily, employees question whether this information will be provided to the HR department or to other administrators with direct bearing on their insurance and employment status. Their concerns focus on the possibility of discrimination. However, administrators have been successful in mediating such concern, simply by reassuring employees that the health system is HIPAA compliant and that the health information will not be inappropriately used. To this end, they emphasize that the information—though available electronically—is accessible to a limited number of people to prevent a breach of confidentiality and effectively protect individual privacy rights.

V. PROFILE: *Third-party contractor maintains sole access to employee health information*

Health system administrators began offering annual HRAs to their employees in 2004. The program is purely voluntary and is handled exclusively by Morehead Associates, a third-party contractor that assumes responsibility for collecting the health information, analyzing it, and following up with employees once the results have been determined. Administrators and staff members within the health system never receive any information pertaining to the outcome of the HRAs. Health system leaders made the decision to outsource all aspects of the HRA specifically to prevent any privacy or ethical concerns from arising.

Third-party contractor informs high-risk employees of results, but employees must decide to act upon the information

Employees provide health information online either at work or at home and submit the HRA electronically to the third-party contractor. Once the contractor has analyzed the information, administrators have a nurse employed by the contractor follow up with high-risk employees. This nurse is responsible not only for informing patients of the outcome of the HRAs but also for encouraging them to inform their PCPs of the results such that they can enroll in an appropriate disease management program. The health system in turn is provided no individual information related to the HRA, though it does receive an overview of the percentage of employees that are deemed at high risk for certain health problems.

Institution type:	2,000-bed, multi-hospital, not-for-profit health system located in the South
Source:	Director, employee health
HRA characteristics:	<ul style="list-style-type: none"> • Distributed and assessed by third-party vendor • Employees responsible for informing PCPs and enrolling in disease management programs
Ethical and privacy concerns:	<ul style="list-style-type: none"> • Discrimination resulting from insurer or employer knowledge of health problems
Strategies to mitigate concerns:	<ul style="list-style-type: none"> • Dissociation from test administration and review of health information • Employ third-party vendor to obtain and assess health information • Voluntary participation

This nurse is responsible not only for informing patients of the outcome of the HRAs but also for encouraging them to inform their PCPs of the results such that they can enroll in an appropriate disease management program. The health system in turn is provided no individual information related to the HRA, though it does receive an overview of the percentage of employees that are deemed at high risk for certain health problems.

Concerns likely to center around inappropriate sharing of information and discrimination

Administrators decided to thus dissociate themselves from the HRA process and keep participation voluntary so as to allay potential concerns or problems with regards to employee privacy. In particular, they speculate that employees would be reluctant to participate in an HRA for fear that the information would be made available to administrators with bearing over their employment status and enrollment in certain benefits. Removing health system administrators from the HRA process and ensuring that individual information is inaccessible to them mitigates this concern and ensures complete privacy protection for employees.

Health system involvement limited to the provision of incentives for participation

Approximately 40 percent of employees participated in the most recent HRA. Administrators attribute this high participation rate in part to the fact that employees have few concerns with regards to the privacy of their health information. However, they likewise note that most probably participate in order to be eligible to receive a number of incentives that are offered. All employees who complete an HRA are automatically enrolled in a raffle through which they can win the following prizes:

- ❖ Gift certificates
- ❖ Computer and printer
- ❖ Cruise vacation for two to the Bahamas
- ❖ Flat screen television
- ❖ Free gas for a year
- ❖ Gym membership
- ❖ Spa gift certificate

Administrators decided to offer these incentives to improve participation in the program. They felt that increased participation would improve the likelihood that at-risk individuals would receive care since these individuals would be notified and educated on the appropriate course of action.

Research Methodology

During the course of research, Original Inquiry staff searched the following resources to identify pertinent information:

- Advisory Board's internal and online (www.advisory.com) research libraries
- Factiva™, a Dow Jones and Reuters company
- Internet, via search engines and multiple websites
 - ✓ American Hospital Directory at www.ahd.com
 - ✓ Health Affairs at www.healthaffairs.com
 - ✓ Health Finder at www.healthfinder.gov
 - ✓ Healthcare Information and Management Systems Society at www.himss.org
 - ✓ Health-Informatics Online at www.healthcare-informatics.com/index.php
 - ✓ The Center for Social and Legal Research at www.pandab.org

Based on leads generated from the sources listed above, researchers contacted administrators who oversee the collection and appropriate use of health information from employees for risk assessments.

Professional Services Note

The Advisory Board has worked to ensure the accuracy of the information it provides to its members. This project relies on data obtained from many sources, however, and the Advisory Board cannot guarantee the accuracy of the information or its analysis in all cases. Further, the Advisory Board is not engaged in rendering clinical, legal, accounting, or other professional services. Its projects should not be construed as professional advice on any particular set of facts or circumstances. Especially with respect to matters that involve clinical practice and direct patient treatment, members are advised to consult with their medical staffs and senior management, or other appropriate professionals, prior to implementing any changes based on this project. Neither the Advisory Board Company nor its programs are responsible for any claims or losses that may arise from any errors or omissions in their projects, whether caused by the Advisory Board Company or its sources. 1-JVQIP

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