Consumer Guide to Understanding and Using the PHR Model Privacy Notice on PHR Company Data Practices

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This Consumer Guide to Understanding and Using the PHR Model Privacy Notice on PHR Company Data Practices is offered for informational and educational purposes only. It is not intended to be a substitute for the privacy, security, and other relevant policies of a PHR company or other organization that provides a PHR. Consumers are strongly encouraged to review such policies in full before choosing a PHR and should not rely on this guide to provide information about specific PHRs and PHR companies.

Introduction

Coordinating and managing your health information is critical when it comes to keeping track of your health and that of your loved ones. One tool available to help you organize all this information is a Web-based personal health record (PHR). Web-based PHRs typically provide the ability for you, your doctor, or both of you to enter or upload information about recent office visits, lab tests, and other health factors. Web-based PHRs also typically allow you to share this information with other doctors and family members or keep it limited to you and only you.

Q: What is a Web-based PHR?

Put simply, a Web-based PHR is an electronic health data application that can help you collect, manage, and share your health information. Web-based PHRs may be offered by physicians, hospitals, your insurance company, employer, or a commercial company.

Q: How can a Web-based PHR help me?

Web-based PHRs offer the potential for you to have your complete medical history in one place and easily accessible to you. In some cases, doctors and hospitals can send a copy of the health records they keep on you to your Web-based PHR. In other cases, you may be able to get an electronic copy of your records from your health care provider or health plan and upload it to your Web-based PHR. Once your health information is in your Web-based PHR, you may be able to share all or portions of the PHR with a new doctor. This may allow them to treat you more effectively and in a more uninterrupted fashion. Sharing your health information with your doctor may be done electronically or by printing a copy of the information from the PHR to bring to your doctor. A Web-based PHR can also make it easier to involve your loved ones in your care, especially if they do not live close to you.

Q: How do I get a Web-based PHR?

Web-based PHRs are offered by a wide variety companies and organizations. Sometimes they are directly offered by your doctor or hospital. Other times, they are offered by your health insurer or employer. Other companies or organizations may also provide Web-based PHRs.

Q: How do I choose a Web-based PHR?

There are many different Web-based PHRs available today. Each Web-based PHR offers a unique combination of features and capabilities to help you organize your health information, communicate with your health care provider, and better manage your health and health care. Each PHR company also has its own set of policies that govern the privacy and security of the data held in the

PHR(s) it offers. Choosing the right PHR involves deciding which PHR fits into your lifestyle, your health needs, and your expectations regarding the privacy and security of your health data in your PHR. The PHR Model Privacy Notice can help you compare some of the key privacy and security policies associated with PHRs.

Q: What privacy and security requirements apply to Web-based PHRs?

Federal and state laws related to privacy and security could potentially apply to the PHR company or other organization providing the Web-based PHR as well as to the information stored in the PHR. In general, the relevant legal requirements will depend upon many different factors, such as who provides the Web-based PHR and in which state(s) they operate. In addition to any requirements imposed by law, a PHR company or other organization providing the Web-based PHR may have its own policies that would affect the privacy and security of your information.

No matter which PHR you choose, it is important to understand the policies that a PHR company has in place to protect your privacy and keep your personal information secure. It is also important to know the PHR company's policies related to when the PHR company would release your PHR Data to other parties or how the PHR company handles your PHR data within the PHR company. For the purposes of this guide, we will refer to the PHR company's privacy and security policies as "data practices."

Follow Jane's story by clicking on the red tabs - Read how Jane chose a Web-based PHR, and how having a Web-based PHR helped her and her son quickly get the right treatment...



Jane's Story Chapter 1 – Jane wants a PHR

Jane is a 35-year-old mother of a 4-year-old boy. She is also the main caretaker of her mother, who has been diagnosed with breast cancer.



Jane reports to her primary care physician that she has been dealing with a cough for the last two months. After a few inconclusive lab tests, Jane's primary care physician decides to send Jane to an ear, nose and throat (ENT) specialist who is located about 40 minutes from her house.

Jane decides that she is going to look for a PHR to help her manage her mother's cancer treatment records, her son's pediatrician records, and results from her recent doctor's visits for her cough.



The PHR Model Privacy Notice – Overview

The Office of the National Coordinator for Health Information Technology (ONC) has created an easy-to-read comparison tool to help consumers review the data practices of companies that offer Web-based PHRs. This comparison tool is called the **PHR Model Privacy Notice**.

If a PHR company provides a PHR Privacy Notice that follows the Model Notice on its website, the notice can be found as a link that states "PHR Privacy Notice" on the homepage of the PHR company's website.



A company's PHR Privacy Notice is expected to look the same no matter which company's website you visit if they use this Model Notice. Below is an example of the PHR Model Privacy Notice.

What are [Company Name]'s [Product Name] PHR data practices?

Use this page to understand how [Company's Name] releases and secures your PHR Data.

| Release | | | | |
|--|-------------|--|------------------|---------------------|
| Do we release your PHR Data for these purposes? | [Yes/No] | We release | Personal Data | Statistical Data |
| Do we require Limiting Agreements that restrict what | [Yes/No/NA] | For marketing and advertising | [Yes/No] | [Yes/No] |
| third parties can do with your Personal Data? | | For medical and pharmaceutical research | [Yes/No] | [Yes/No] |
| Do we stop releasing your Personal Data if you close or transfer your PHR? | [Yes/No/NA] | For <u>reporting</u> about our company and our customer activity | [Yes/No] | [Yes/No] |
| | | For your insurer and employer | [Yes/No] | [Yes/No] |
| Secure | | For developing software applications | [Yes/No] | [Yes/No] |
| We have security measures that are reasonable and approtect personal information, such as PHR Data, in any tunauthorized access, disclosure, or use. | | | | |
| Do we store PHR Data in the U.S. only? | [Yes/No] | | | |
| Do we keep PHR Data activity logs for your review? | [Yes/No] | | | |

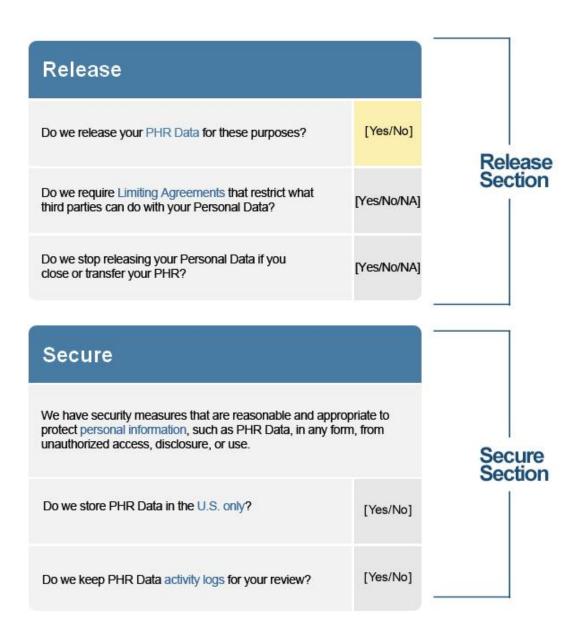


Chapter 2 – Which PHR to choose?

Jane is trying to decide between the PHRs offered by YourOwnHealth and HealthDataManager. Jane decides to compare each company's PHR Model Privacy Notice to help her choose the PHR offered by the company that has data practices that best fit her personal preferences for privacy and security.

The PHR Model Privacy Notice has two sections: 1) the "Release" section, and 2) the "Secure" section. These sections tell you what the PHR company may do with your PHR Data. PHR Data is any information in your PHR that is about you.

The "Release" section describes the PHR company's data-sharing practices for certain purposes. This section also includes certain restrictions the PHR may have in place for releasing your PHR data. The "Secure" section describes some of the PHR company's data security practices.



Q: Why would a PHR company send my PHR Data to someone else?

A PHR company may release your PHR Data for various reasons. For example, a PHR company may be required by law to release some of your PHR Data to the Centers for Disease Control and Prevention (CDC) during a dangerous epidemic. In some cases, however, it may be the PHR company's business practice to release your PHR data for different reasons, such as selling your PHR Data to research and marketing organizations. In either case, your PHR Data may be released in the form of either Personal or Statistical Data. You can learn more about these two forms of PHR Data in the section below. If you do not want your PHR Data to be released for certain purposes, you can contact the PHR company to learn whether they provide you the opportunity to, for example, "opt-out" of the data sharing they engage in with your information.

The Release Section

Release Section Question 1 – "Do we release your PHR Data for these purposes?"

If a PHR company answers "Yes" to this question, it means that the PHR company releases your PHR Data for at least one of the purposes listed in the yellow table. The yellow table's specific rows are explained in the next section of this guide. If a PHR company answers "No," it means that the PHR company does not release your PHR Data for any of the purposes listed in the yellow table, except as part of permissible company operations. Permissible company operations include the internal use of or external release of your PHR data by the PHR company to comply with federal or state laws or to manage, maintain, or protect the PHR company's computer system and website.

Release Section – Yellow Table

The yellow table (to the right of the question "Do we release your PHR Data for these purposes?") shows you certain purposes for which the PHR company releases your data.

The yellow table also tells you whether the data released by the PHR company is Personal Data or Statistical Data. This PHR Model Privacy Notice only covers releases for the purposes specified in the yellow table. Typically, the PHR company's full privacy policy will have more detail about releases of information and whether your PHR Data is released for purposes that are not included in the yellow table.

If the PHR company does release your data, either in the form of Personal or Statistical Data, you may wish to review their full privacy policy which is linked to this Notice or contact the PHR company to find out if they give you the opportunity to "opt-out" of releasing your information. "Opt-out" means that you are able to tell the PHR company that you do not want them to release your PHR data with certain companies or with anyone at all. If the PHR company releases your data, it must answer "Yes" to the first question of "[Do] we release your PHR Data for these purposes," and "Yes" to any Personal or Statistical Data they release, even if you have an opportunity to opt-out. The reason they must answer "Yes" is because until you "opt-out" of releasing your information, the PHR company may release your PHR Data.

Furthermore, if the PHR company requests or requires your permission to release your PHR data for the purposes in the yellow table when you sign up for their PHR or other PHR-related services, the PHR company must answer "Yes" in this Release section.

| Release | | | | |
|--|-------------|--|----------------------------------|---------------------|
| Do we release your PHR Data for these purposes? | [Yes/No] | We release | Personal Data | Statistical Data |
| Do we require Limiting Agreements that restrict what | [Yes/No/NA] | For marketing and advertising | [Yes/No] | [Yes/No] |
| third parties can do with your Personal Data? | [| For medical and pharmaceutical research | [Yes/No] | [Yes/No] |
| Do we stop releasing your Personal Data if you close or transfer your PHR? | [Yes/No/NA] | For reporting about our company and our customer activity | [Yes/No] | [Yes/No] |
| soot of allowayear reactions | | For your insurer and employer | [Yes/No] | [Yes/No] |
| | | For developing software applications | [Yes/No] | [Yes/No] |
| | | This table helps you on what PHR data is being and for what purpose data is being released | determir ng releas your Ph | ne sed HR |



Chapter 3 – The Yellow Table

Jane sees that both PHR companies answered "Yes" to the question, "Do we release your PHR Data for these purposes?" Jane then decides to look at the yellow table to compare to whom the PHR company may release her Personal or Statistical Data.

When reviewing this yellow table on the PHR company's release data practices, you should understand the following terms and sections:

Q: What is Personal Data?

Personal Data is any PHR Data that connects to you as an individual, such as names, health conditions, and other identifiers. When a PHR company says that it releases your personal data, this means the company releases information about you and only you whether or not it can be used to identify you.

- Your name and contact information
- Your medical history, conditions, treatments, and medications
- Your health care claims information, health plan account numbers, medical bills, and insurance information

- Demographic information, such as your age, gender, ethnicity, and occupation
- Computer information, such as your Internet Protocol (IP) address and "cookie" preferences

| We release | Personal Data | Statistical Data | |
|---|---|---|---|
| For marketing and advertising | [Yes/No] | [Yes/No] | |
| For medical and pharmaceutical research | [Yes/No] | [Yes/No] | |
| For reporting about our company and our customer activity | [Yes/No] | [Yes/No] | |
| For your insurer and employer | [Yes/No] | [Yes/No] | |
| For developing software applications | [Yes/No] | [Yes/No] | |
| | This see Persona released compar | ction tells al Data is d by the l ny for the | s you if your being PHR ese purpose: |

Your Personal Data released from your PHR may look like this:

| ON |
|------------------------|
| (First) (Mide |
| Jane . |
| |
| Smith |
| |
| Sample Ln |
| State Zip Code Country |
| NY 55055 USA |
| |
| 5) 555-5555 |
| |
| 4) 444-4444 |
| |
| oe@email.com |
| Male / Female |
| Female |
| Ethnicity |
| Caucasian |
| |
| 555 |

| | MOTHER | FATHER | SIBLING | GRAND PARENT | CHILD |
|---------------------------|--------|--------|---------|-----------------|-------|
| Alcoholism | | | | | |
| Arthritis | | | | | |
| Asthma | | | | | X |
| Cancer | X | | | | |
| Diabetes | | | | | |
| Heart Condition | | | | | |
| Hepatitis | | | | | |
| High Cholesterol | x | | x | | |
| High Blood Pressure | | | | | |
| Kidney Disease | | | | | |
| Smoking | | | | | |
| Stroke | | | | | |
| | | | | | |

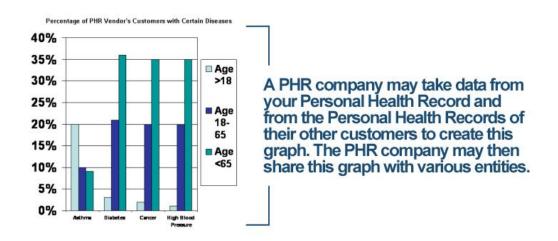
Q: What is Statistical Data?

Statistical Data is PHR Data that is 1) grouped so that it does not connect to you as an individual **and** 2) has names and other identifiers removed or altered. When a PHR company says that it releases Statistical Data, this means the company uses your PHR Data and combines it with PHR Data from many other individuals. When creating Statistical Data, the PHR company will also either eliminate or change information that would link you to the data. For example, if a PHR company releases information to a medical researcher about how many of its customers between the ages of 45-65 have high blood sugar (an indicator for diabetes), the PHR company will get this data from your Web-based PHR and group it together with others' PHR Data.

| We release | Personal Data | Statistica Data |
|--|------------------|--------------------|
| For marketing and advertising | [Yes/No] | [Yes/No] |
| For medical and pharmaceutical research | [Yes/No] | [Yes/No] |
| For <u>reporting</u> about our company and our customer activity | [Yes/No] | [Yes/No] |
| For your insurer and employer | [Yes/No] | [Yes/No] |
| For developing software applications | [Yes/No] | [Yes/No] |

This section tells you if your Statistical Data is being released by the PHR company for these purposes.

Someone looking at Statistical Data may see the following:



Release Section Question 1 – Subcategories

- a. Marketing and Advertising
- b. Medical and Pharmaceutical Research
- c. Reporting of Company and Customer Activity
- d. Insurers and Employers
- e. Software Application Development

Marketing and Advertising:

In order to design more effective and specific ads about new or existing medications, treatments, or products that may pertain to your health issues, marketing and advertising companies may seek information about certain health conditions a PHR company's users may have. PHR companies who share your data with marketing and advertising organizations may be compensated by such organizations for the data they receive from your PHR.

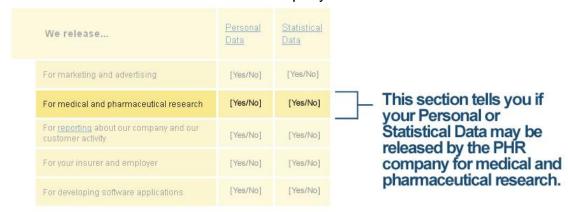


Jane sees that neither company gives out her PHR Data in any form for marketing or advertising. So Jane likes that she will not receive ads for any products based on the data she stores in her Web-based PHR. However...

| We release | Personal Data | Statistical Data |
|--|------------------|---------------------|
| For marketing and advertising | [Yes/No] | [Yes/No] |
| For medical and pharmaceutical research | [Yes/No] | [Yes/No] |
| For <u>reporting</u> about our company and our customer activity | [Yes/No] | [Yes/No] |
| For your insurer and employer | [Yes/No] | [Yes/No] |
| For developing software applications | [Yes/No] | [Yes/No] |

Medical and Pharmaceutical Research:

This section allows you to see if the PHR company shares your personal or statistical data for medical and pharmaceutical research. Medical and pharmaceutical researchers may be interested in looking at PHR Data to help them analyze the effectiveness of medications and treatments, or identify adverse reactions. PHR companies who share your data with medical or pharmaceutical researchers may be compensated by the research organization for the data it receives from the PHR company.





Chapter 5 – Jane's son gets sick

Within the last week, Jane's son starts coughing as well. She takes him to see the pediatrician who runs a few lab tests. These tests also come back inconclusive, so the pediatrician suggests that Jane take her son to see an ENT specialist as well. With the need to see an ENT specialist for both her and her son, Jane decides to find an ENT specialist closer to her house. In

the meantime, Jane continues her research to find the right Web-based PHR to manage her family's health.

The yellow table shows Jane that *HealthDataManager* releases her Personal Data and Statistical Data for medical and pharmaceutical research. The thought of her Personal Data being released without her knowledge for medical and pharmaceutical research begins to worry her. *YourOwnHealth*, on the other hand, only releases Statistical Data for medical and pharmaceutical research.

Jane's about to select YourOwnHealth's PHR, until she notices that...

Reporting of Company and Customer Activity:

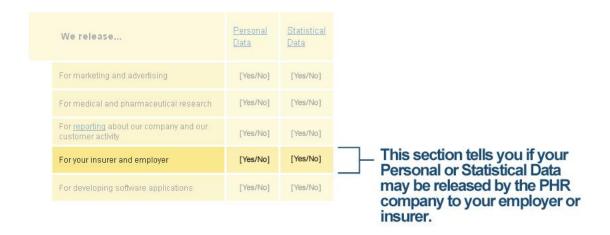
Companies sometimes monitor how their Web-based PHR is being used by their customers. They want to know if and why their customers like their Web-based PHRs and its features. If a company finds that its Web-based PHR has been helpful to many of its customers who have diabetes, the company may want to inform other people with diabetes that its Web-based PHR may be helpful to them as well. The PHR company will not only want to know that you are using your Web-based PHR to better manage your diabetes, but also want to know what features in the PHR are helping you the most with managing your diabetes.

| We release | Personal Data | Statistical Data |
|--|------------------|---------------------|
| For marketing and advertising | [Yes/No] | [Yes/No] |
| For medical and pharmaceutical research | [Yes/No] | [Yes/No] |
| For <u>reporting</u> about our company and our customer activity | [Yes/No] | [Yes/No] |
| For your insurer and employer | [Yes/No] | [Yes/No] |
| For developing software applications | [Yes/No] | [Yes/No] |

Insurer or Employer:

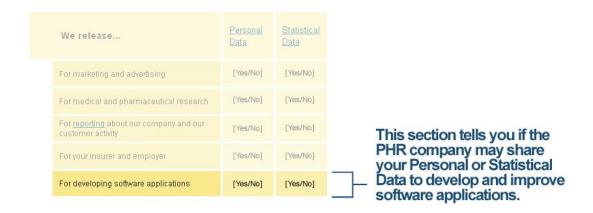
This section allows you to see if the PHR company shares your Personal or Statistical Data with insurers or employers. This section includes releases of your PHR Data by the PHR company to your insurer or employer when your PHR company and your insurer or employer are part of the same organization. In this situation, the part of the organization that manages the PHR may have strict policies that limit or prohibit whether other parts of the organization can receive

Personal or Statistical Data from your PHR. If the Personal Data or Statistical Data boxes for this row are marked "Yes," it means that your PHR company shares one or both of these types of data with your insurer or employer.



Software Application Development

This section allows you to see if the PHR company shares your Personal or Statistical Data for software application development. PHR companies may share their customers' Personal Data or Statistical Data with software application developers who create add-on software that works with the PHR. The PHR company may also share your PHR Data to improve the functionality or usability of the PHR interface, or to improve the capabilities of the PHR for its users.



Release Section – Limiting Agreements

Q: What are Limiting Agreements?

A Limiting Agreement is a legally binding agreement, such as a contract, between the PHR company and the recipient of your Personal Data that prevents

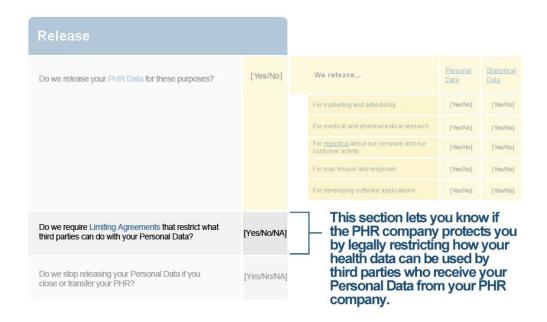
the recipient from further releasing your PHR Data. For example, if the PHR company gives your information to a software application developer to develop a weight-loss application for its PHR users, the PHR company could require in a limiting agreement that the software application developer cannot further release your PHR Data to another company. If the answer to the question above, "Do we release your PHR Data for these purposes?" is "No", the answer to this question will be N/A, or not applicable.

Jane's Story Chapter 6 – Jane wants limits

Jane sees that YourOwnHealth does not require limiting agreements with the companies with whom it shares its customer data. This information makes Jane reconsider HealthDataManager.

Although Jane did not like that *HealthDataManager* may share her Personal Data for medical and pharmaceutical research, HealthDataManager does put limiting agreements in place to make sure Jane's information is not released beyond the initial recipient.

On the other hand, YourOwnHealth does not have Limiting Agreements in place when they releases Jane's PHR Data to other companies. Jane takes a look at the last portion of the Release section to help inform her decision...



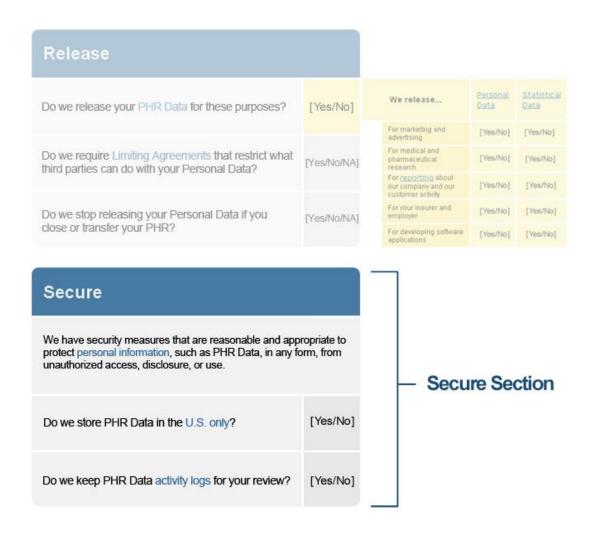
Release Section - After Closing or Transferring your PHR

You may want to know what the PHR company does with your PHR Data once you close your PHR account and transfer your PHR information to another PHR company. If a PHR company says "Yes" in this section, it means that the PHR company will not release your PHR Data with anyone for any purpose after you close or transfer your PHR. If a company says "No," then it is retaining a copy of your PHR Data and continuing to release it with other entities after you close or transfer your PHR. If the answer to the question above, "Do we release your PHR Data for these purposes?" is "No", the answer to this question will be N/A, or not applicable.

| Release | | | | |
|--|-------------|---|------------------|---------------------|
| Do we release your PHR Data for these purposes? | [Yes/No] | We release | Personal Data | Statistical Data |
| | | For marketing and advertising | No | No |
| | | For medical and pharmaceutical research | Yes | Yes |
| | | For reporting about our company and our customer activity | No | No |
| | | For your insurer and employer | No | Yes |
| | | For developing software applications | Yes | No |
| Do we require Limiting Agreements that restrict what third parties can do with your Personal Data? | [Yes/No/NA] | This section lets you | ou knov | w if |
| Do we stop releasing your Personal Data if you close or transfer your PHR? | [Yes/No/NA] | release your Personafter you close or to PHR. | onal Dat | ta |

The Secure Section

The Secure section includes three points to help you identify the PHR company's data security practices. More specifically, it identifies that the PHR company implements security measures; whether the PHR company stores PHR Data in the United States only; and whether the PHR company keeps activity logs that record the history of who accesses your PHR and when they access it. This last point indicates whether you'll be able to review the activity logs yourself.



Q: What are security measures?

Generally speaking, security measures are procedures and technologies a PHR company uses to keep unauthorized persons from being able to access or view your PHR Data.

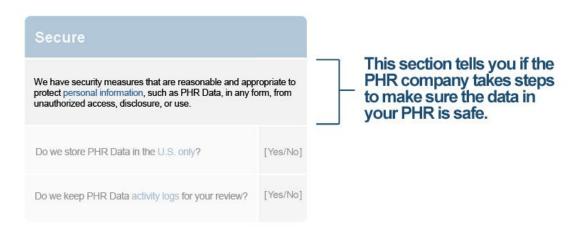
Secure Section – The Security Measures Clause

The security measures clause, in the first row of the Secure section states, "We have security measures that are reasonable and appropriate to protect personal information, such as PHR Data, in any form, from unauthorized access, disclosure, or use." PHR companies must follow this statement and have reasonable protections in place if they post this PHR Model Privacy Notice on the company's website. PHR companies that do not use this PHR Model Privacy Notice may or may not have such security measures in place.

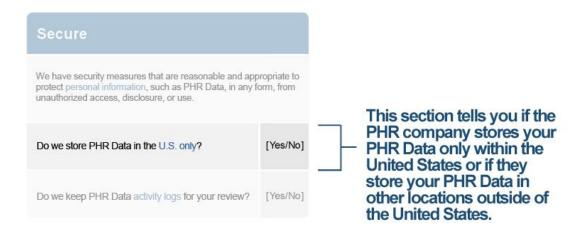
Q: What is the difference between PHR Data and personal information?

PHR Data is any data that is within your PHR. The PHR company may have additional information about you that is not stored in your PHR. This "personal information" can include, but is not limited to, your credit card information that

you gave the company to pay for your monthly fee of using the company's PHR system. You will want to know if the PHR company is protecting your data regardless of whether it is data within your PHR or the PHR's company's billing records.



Secure Section – Question 1 – Do we store PHR Data in the U.S. only? Although a PHR company may operate in the United States, it may also have business operations outside of the United States. For example, some PHR companies may have employees in the United States as well as other countries and may also store your data in computers in the United States and in other countries. If a PHR company answers "Yes" to this question, it means that the PHR company only stores PHR Data within the United States. If the PHR company answers "No" to this question, it means that the PHR company could store some or all of its customers' PHR Data outside the United States. You may care about this because it may affect whether U.S. laws apply to the protection of your PHR data.

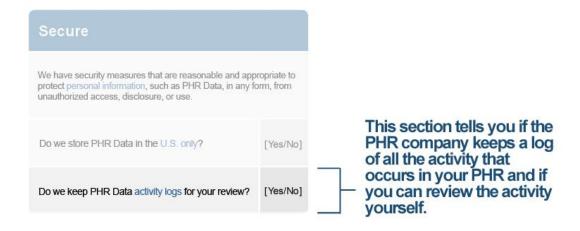


Secure Section – Question 2 – Do we keep PHR Data activity logs for your review?

This section tells you if a PHR company keeps logs of activity (such as data access, updates, data transfers) within your PHR <u>and</u> allows you to review this log. If a PHR company answers "Yes" to this question, it means that the company keeps an activity log <u>and</u> allows you to see a copy of this log in a timely manner. If a PHR company says "No" in this section, it could mean that the company either: 1) does not keep activity logs at all; or 2) does keep activity logs, but does not have a way for you to review these activity logs.

Q: Can I get additional information on the PHR company's data practices?

In addition to this PHR Model Privacy Notice, you also may want to take the time to review all of the data sharing practices and security measures that the company is taking. These are often in a document call a "privacy policy". You can find this by clicking on the link at the end of the PHR Privacy Notice. Privacy policies do not ensure privacy, but explain privacy and security practices of a company. Most PHR companies have supplementary information on their Web site explaining their data sharing practices. You may also be able to get information by calling or writing to the PHR company.





Chapter 7 – Jane gets better

Based on all the information Jane had from the PHR Model Privacy Notice, Jane is able to choose a PHR according to her privacy preferences. Having peace of mind about the privacy and security of her PHR Data, Jane could now focus on getting medical care she wanted for her and her family.

In the weeks to follow, Jane is able to use her PHR to keep all her doctors up to date on the medical events that took place over the last couple months. She has easily been able to send her and her son's medical charts to her primary care physician, ENT specialist, and her son's pediatrician. This prevented her doctors from reordering the same tests and saved time before formulating the diagnosis. They find out that Jane's son is not wheezing from his asthma, but rather has picked up Jane's bronchial infection. Jane's son is saved from unnecessary asthma treatments and is given the appropriate antibiotics in a timely fashion. Although a PHR may not always alter the medical care a patient receives, in Jane's case, her PHR helped her receive better medical care for her family.

Jane was fortunate that all her providers allowed her to send them information from her PHR and that all her records were compatible with her PHR. More people are using PHRs to manage their health information and PHRs are becoming more capable of functioning like Jane's PHR.