

PHR Model Privacy Notice Implementation Guide

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I. Introduction

The Office of the National Coordinator for Health Information Technology (ONC) is issuing this PHR Model Privacy Notice implementation guide to provide PHR companies with detailed instructions for how to correctly populate and subsequently display the PHR Model Privacy Notice. In the PHR Model Privacy Notice and this implementation guide, the term “PHR company” refers to any organization, public or private, that offers a web-based PHR. ONC has established the following website (http://healthit.hhs.gov/PHR_Privacy) that allows PHR companies to easily create a company-specific or product specific PHR Privacy Notice.

The PHR Model Privacy Notice was created by ONC to provide PHR consumers with information regarding a PHR company’s data sharing and data security practices for that company’s particular PHR product. The at-a-glance content and design of this PHR Model Privacy Notice is meant to provide information to consumers in a uniform layout they can understand, compare, and use to make an informed decision on which PHR they would like to use. This notice has undergone formative and cognitive usability consumer research tests to meet these goals. The PHR Model Privacy Notice focuses on a PHR company’s policies for when PHR Data are released out of a consumer’s PHR for certain purposes by the PHR company. The notice does not cover PHR features offered by the PHR company to the consumer that enable the consumer to direct the release of PHR Data out of their own PHR. The notice also does not address specific differences in privacy policies that may affect information about minors. The questions in this PHR Model Privacy Notice refer to handling of data from the consumers’ PHR by the PHR company. Only the statement under the “Secure” section that reads “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” pertain to all data that the PHR company has related to the consumer.

Use of this PHR Model Privacy Notice is voluntary. However, ONC believes that providing transparency regarding company practices with respect to PHR data will allow consumers to develop trust in PHRs and be more likely to use them. It is essential that PHR Model Privacy Notices are populated and displayed in a consistent fashion. To ensure this consistency, ONC recommends that PHR companies who choose to use this PHR Model Privacy Notice do so by following the instructions in this ONC implementation guide.

ONC believes that the accuracy of the information provided in a company’s PHR Privacy Notice is important to foster consumer trust. ONC requests that PHR companies periodically revisit their displayed PHR Privacy Notice to ensure the accuracy of responses. In addition, when company policies change related to the responses in the PHR Model Privacy Notice, the PHR company should update the notice in a timely manner. If a PHR company’s notice is outdated, it should pull down any inaccurate company PHR Privacy Notices and create new notices through

http://healthit.hhs.gov/PHR_Privacy. It is suggested that changes in the PHR Privacy Notice should be prospective only.

The Model Privacy Notice and this PHR Model Privacy Notice Implementation Guide are offered for informational purposes only. They are not intended to be a substitute for the privacy, security, or other policies of a PHR company or other organization. This guide does not offer advice with regard to the content of such policies. Use of the PHR Model Privacy Notice does not exempt PHR companies or other organizations from compliance with privacy, security, or other requirements imposed by law. Users of the PHR Model Privacy Notice and this guide are strongly encouraged to consult with their legal counsel with regard to the development of their organizational policies.

Companies are responsible for ensuring the accuracy of answers to their PHR Privacy Notice(s). For example, if the company releases PHR data to marketing organizations but answers “no” to releasing PHR data for marketing purposes, then the company is providing inaccurate information to the prospective and current customers. A PHR Model Privacy Notice is considered a communication between the PHR company and its prospective and current customers. Incorrect information may have legal implications for the PHR company. Under the FTC Act, the Federal Trade Commission has authority to challenge false or misleading representations to consumers.

II. Instructions to Generate PHR Model Privacy Notice

A. Go to http://healthit.hhs.gov/PHR_Privacy and review the PHR Model Privacy Notice template. Then review this guide to gather answers to questions in PHR Model Privacy Notice.

A template of the PHR Model Privacy Notice can be found at http://healthit.hhs.gov/PHR_Privacy. PHR companies should work with their legal, privacy, security, marketing, and other relevant business divisions to understand the company’s practices so they can accurately populate answers to create their customized PHR Privacy Notice. Once the company’s data and security practices have been determined the PHR company should work with its web team to populate the answer fields in the ONC web-based template according to the implementation guide and generate and then display its PHR notice(s) on its company communication materials and website.

B. Enter company information and PHR Model Privacy Notice answers to generate customized PHR Model Privacy Notice:

Section I: Entering Company Information

What are your organization's PHR data practices?

This survey will generate an HTML page and optional PDF you can use to help your users or customers understand how your organization releases and secures their [PHR Data](#).

Company Information

Company Name:

Company Image URL:
(Will be displayed at 100px width.)

Company Phone:

Company Email:

PHR Product Name(s):

Privacy Policy URL:

- Step 1.** Enter company specific name as your company wants it to appear on publicly disseminated materials. Once entered, the company name will be automatically inserted in the title, subtitle, and footer box of the PHR Model Privacy Notice. The footer box, located at the end of the PHR Model Privacy Notice includes the company's name, phone number, and email address.
- Step 2.** Enter a URL where the company's logo is located into the text box titled "Company Image URL." The company logo will be automatically inserted in the upper left hand corner of the PHR Model Privacy Notice.
- Step 3.** Enter the company's phone number where consumers can obtain further information regarding the company's data practices.
- Step 4.** Enter the company's email address through which consumers can obtain further information on the company's information release and data security practices and policies.
- Step 5.** Enter the name of the PHR product into the text box titled "PHR Product Name." If the PHR company has more than one PHR product, but the company's data practices do not differ between the products, the PHR company can add the relevant PHR product names in this text box. If the PHR company's data practices differ between PHR products, the PHR

company should use separate PHR Privacy Notices to ensure that the information in the notice is accurate in relation to the specified PHR product.

Step 6. Enter the URL to the company's full privacy policy. This URL will not be directly displayed in the PHR Model Privacy Notice. Instead the phrase "full privacy policy" located at the bottom of the PHR Model Privacy Notice will be hyperlinked to the company's full privacy policy URL. This URL must be the most current URL for the company's full privacy policy.

Section II: Answering Release Section Questions

The "Release" section intends to provide a snapshot of a PHR company's practices of releasing PHR Data from an individual's PHR for specific purposes. "PHR Data" refers to any data submitted or collected in the process of using a PHR. This includes information the customer fills in as well as information that is automatically populated by the PHR or automatically collected, such as IP addresses gathered from cookie placement.

The term "Release" refers to any transmission or sharing of PHR Data by the PHR company within the PHR company or externally to partners, third parties, etc., for any purposes outlined in the yellow table of the PHR Model Privacy Notice (yellow table is explained in the next section) and that falls outside of operational use. Operational use [as tested and understood by consumer research] of PHR Data includes: 1.) Operating and managing the PHR platform, software, and website, 2.) Maintaining and protecting the computer systems, and 3.) Complying with the law, such as responding to subpoenas and search warrants. For example, sharing PHR Data internally with the company's marketing division or externally with an advertising company is considered a release. However, sharing PHR Data with the company's IT team to maintain PHR Data security is not considered a release with regard to this PHR Model Privacy Notice. If PHR data is released, as described above, the PHR company must answer "yes" even if they provide an opt out or if the individual "accepts" the privacy policies as a condition of signing up for the PHR product. Sharing of PHR Data solely at the request of the individual who created the PHR is not considered a release for purposes of this notice.

Release	
Do we release your PHR Data for these purposes?	<input type="radio"/> Yes <input type="radio"/> No
Do we require Limiting Agreements that restrict what third parties can do with your Personal Data?	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> N/A
Do we stop releasing your Personal Data if you close or transfer your PHR?	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> N/A

We release...	Personal Data	Statistical Data
For marketing and advertising	<input type="radio"/> Yes <input type="radio"/> No	<input type="radio"/> Yes <input type="radio"/> No
For medical and pharmaceutical research	<input type="radio"/> Yes <input type="radio"/> No	<input type="radio"/> Yes <input type="radio"/> No
For reporting about our company and our customer activity	<input type="radio"/> Yes <input type="radio"/> No	<input type="radio"/> Yes <input type="radio"/> No
For your insurer and employer	<input type="radio"/> Yes <input type="radio"/> No	<input type="radio"/> Yes <input type="radio"/> No
For developing software applications	<input type="radio"/> Yes <input type="radio"/> No	<input type="radio"/> Yes <input type="radio"/> No

Secure	
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.	
Do we store PHR Data in the U.S. only ?	<input type="radio"/> Yes <input type="radio"/> No
Do we keep PHR Data activity logs for your review?	<input type="radio"/> Yes <input type="radio"/> No

Step 1. Indicate if your company releases PHR data to any of the entities in the yellow “Reasons” table and if the released PHR data is Personal or Statistical Data (as defined in the section above). You must first populate the yellow “Reasons” table (yellow section on the right of the “Release” section) before you can determine a Yes/No answer to “Do we release your PHR Data for these purposes?” This yellow “Reasons” table indicates for which purposes PHR data is released and what form the PHR data is in at the time of release. This table is meant to give transparency to a company’s “Yes/No” answer for the question “Do we release your PHR Data for these purposes?” The PHR Model Privacy Notice focuses on PHR Data releases for the following five purposes:

- **Marketing and Advertising** – “For marketing and advertising” includes any internal and/or external marketing, advertising, surveys, coupons, or any other promotions for which PHR data – either personal or statistical- may be released by the PHR company.
- **Medical and pharmaceutical research** – “For medical and pharmaceutical research” includes any for-profit and not-for-profit enterprises, internal or external, engaged in medical, treatment, drug, equipment, device, or comparative effectiveness studies or for the recruitment of such studies.
- **Reporting of Company and Customer Activity** – “For reporting about our company and our customer activity” includes any and all reports made for any internal or external use or transfer of data that

isn't a basic computer operation (as defined under "PHR Data") or a customer directive/request. This area can be considered a catch-all reason to cover any other reasons that PHR Data is used or transferred.

- **Insurer or Employer** – "For your insurer and employer" includes the PHR data customer's current, prospective, and past employers or insurers. If the PHR company is also either the employer or insurer for an individual or an affiliate of such, this question will also apply to access by the employer or insurer component/division.
- **Software Developers** – "For developing software applications" includes all applications or any web/ or mobile "app" development for the company or for/by any third party. The company should also consider whether this practice may also indicate a "Yes" in the other reason categories if, for instance, the "apps" are also used for practices such as marketing, research, etc.

In addition, this PHR Model Privacy Notice allows companies to specify if the PHR data is released as "Personal Data," "Statistical Data" or both. In regards to this PHR Model Privacy Notice, Personal Data and Statistical Data are defined as follows:

- **Personal Data** – The term "Personal Data" refers to any PHR Data that is linked to the consumer as an individual person, computer, or device such as names, health conditions, and other identifiers. For example, Personal Data would include results from a laboratory report even if the name and other information is deleted.
- **Statistical Data** – The term "Statistical Data" refers to PHR Data that is BOTH 1) de-identified according to the process set out in the HIPAA Privacy Rule, and 2) grouped in the aggregate by category or subset of people. For example, Statistical Data may show the average age of diabetic PHR users.

Yellow Reasons Table:

We release...	Personal Data	Statistical Data
For marketing and advertising	<input type="radio"/> Yes <input type="radio"/> No	<input type="radio"/> Yes <input type="radio"/> No
For medical and pharmaceutical research	<input type="radio"/> Yes <input type="radio"/> No	<input type="radio"/> Yes <input type="radio"/> No
For reporting about our company and our customer activity	<input type="radio"/> Yes <input type="radio"/> No	<input type="radio"/> Yes <input type="radio"/> No
For your insurer and employer	<input type="radio"/> Yes <input type="radio"/> No	<input type="radio"/> Yes <input type="radio"/> No
For developing software applications	<input type="radio"/> Yes <input type="radio"/> No	<input type="radio"/> Yes <input type="radio"/> No

Step 2. The “Yes/No” option for “Do we release your PHR Data for these purposes?” will be automatically populated based on the company’s answers in the yellow table. If the PHR Company releases Personal Data or Statistical Data (as these terms are defined in this implementation guide) for the purposes listed in the yellow table, the answer to “Do we release your PHR Data for these purposes?” will be “Yes.” If the company does not release personal data or statistical data (as defined in this implementation guide) to any entity in the yellow table, the answer to the “Do we release your PHR Data for these purposes?” is No. Additionally, if the overall answer to the question “Do we release your PHR Data for these purposes?” is “No,” then the two following steps/questions are not applicable and the template will be automatically populated with “N/A” (not applicable) for the two questions that follow.

Step 3. Enter whether the company has Limiting Agreements in place with all the parties (outside of the consumer) with whom the company shares Personal Data. The PHR company can skip this step if the PHR company answers “No” for “Do we release your PHR Data for these purposes?” (Step 1 and 2) because the template will automatically be populated with “N/A” (not applicable) for this question regarding Limiting Agreements.

The “Yes/No” answer for “Do we require Limiting Agreements that restrict what third parties can do with your Personal Data?” is an all-or-nothing answer. As defined in the PHR Model Privacy Notice, limiting agreements are contracts that strictly prohibit third parties from re-releasing Personal Data or re-identifying individuals. Third parties can include advertisers, researchers, and others who receive Personal Data from the PHR company. The PHR company must require Limiting Agreements from all third parties, to answer “Yes.”

Step 4. Enter whether the company releases Personal Data to anyone (outside of federal or state legal requirements) for any reason after the PHR account has been closed or transferred to another company. The PHR company can skip this step if the PHR company answers “No” for “Do we release your PHR Data for these purposes?” (Step 1 and 2) because the template will automatically be populated with “N/A” (not applicable) for this question about releasing PHR Data after the PHR account has been closed or transferred.

Step 5. To answer “Yes,” Company must have in place a policy to not further release, sell, share, rent or trade any Personal Data (as defined in this PHR Model Privacy Notice and by the ONC implementation guide) of any person who has closed, transferred, deactivated, or deleted his/her PHR from the company. Internal data uses must conform to posted closing/transferring policies. If a PHR company does not have such a policy in place, the company must answer “No.”

Section III: Answering Secure Section Questions

Secure	
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.	
Do we store PHR Data in the U.S. only ?	<input type="radio"/> Yes <input type="radio"/> No
Do we keep PHR Data activity logs for your review?	<input type="radio"/> Yes <input type="radio"/> No

Step 1. Enter whether the company stores all PHR Data only in the US. If the company stores any PHR Data in servers located outside of the US, but not on foreign land, water, or space, the company must still enter “yes” in this section. For example, if a company stores PHR Data in servers located in neutral waters, this is considered “outside of the US.”

Step 2. Enter whether the company keeps activity logs for the PHR customer’s review.
To answer “Yes,” the company makes available to its PHR customers an Activity Log of all its PHR releases, views, transfers, etc. including activity directed and approved by the customer or uses and releases of PHR Data by PHR company. This log must be easily accessible to the PHR consumer through a PHR function or by request to the PHR company. If the activity log is available only by request, the PHR company must be able to supply the activity log to the consumer within a reasonable time or as required by law in order to be able to enter “yes” in this section.

Section IV: Additional information for companies to note

1. Required statement under “Secure” section: The statement under the “Secure” section that reads “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” is the minimum requirement for security for the PHR company to uphold before they are

eligible to use the PHR Model Privacy Notice. Unlike the rest of the PHR Model Privacy Notice, this statement refers to all personal information, which includes PHR Data.

2. Footer information: This section states, “The practices described in this notice only apply to [Company Name] and its service providers. These practices do not apply to any other organizations, links, web sites, programs, or applications that may be available through [Company Name] or its service providers. Always read the policies of any company, web site, application, or service where you provide your Personal Information. This notice is not intended to be a substitute for communicating the full privacy and security policies of [Company Name]. We encourage you to learn more about our privacy and security policies (including options that may allow you to opt out), by visiting our full privacy policy.” As this section states, the answers in this PHR Model Privacy Notice apply to both the PHR company and their service providers. Answers in the company’s PHR Privacy Notice do not apply to other links, sites, programs or applications that the company offers. PHR companies typically will have a complete “privacy policy” and/or notice of privacy practices in place for customers to review. The PHR company’s full privacy policy is separate from and likely more detailed than the PHR Model Privacy Notice. Use of the PHR Model Privacy Notice is not intended to satisfy legal requirements addressed by a complete privacy policy nor is it intended to replace these notices. The PHR company will link its privacy policy webpage to its PHR Privacy Notice by entering the URL for the company privacy policy website on http://healthit.hhs.gov/PHR_Privacy as instructed in step 6 under Section 1 of this implementation guide.

Release		We release...	Personal Data	Statistical Data
Do we release your PHR Data for these purposes?	<input type="radio"/> Yes <input type="radio"/> No			
Do we require Limiting Agreements that restrict what third parties can do with your Personal Data?	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> N/A	For marketing and advertising	<input type="radio"/> Yes <input type="radio"/> No	<input type="radio"/> Yes <input type="radio"/> No
Do we stop releasing your Personal Data if you close or transfer your PHR?	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> N/A	For medical and pharmaceutical research	<input type="radio"/> Yes <input type="radio"/> No	<input type="radio"/> Yes <input type="radio"/> No
		For reporting about our company and our customer activity	<input type="radio"/> Yes <input type="radio"/> No	<input type="radio"/> Yes <input type="radio"/> No
		For your insurer and employer	<input type="radio"/> Yes <input type="radio"/> No	<input type="radio"/> Yes <input type="radio"/> No
		For developing software applications	<input type="radio"/> Yes <input type="radio"/> No	<input type="radio"/> Yes <input type="radio"/> No

Secure	
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.	
Do we store PHR Data in the U.S. only ?	<input type="radio"/> Yes <input type="radio"/> No
Do we keep PHR Data activity logs for your review?	<input type="radio"/> Yes <input type="radio"/> No

III. Instructions to Download and Display PHR Model Privacy Notice

1. Download the company-specific PHR Privacy Notice generated on http://healthit.hhs.gov/PHR_Privacy.

Once this information is filled in, the company can press “Submit” and the http://healthit.hhs.gov/PHR_Privacy site will automatically generate a PHR Privacy Notice specific to the company’s data practices and that reflects the data entered by the company. http://healthit.hhs.gov/PHR_Privacy will generate both (1) a PDF version of the company’s PHR Privacy Notice and (2) an HTML file of the company’s PHR Privacy Notice. The HTML version of

the PHR Model Privacy Notice was embedded with consumer-tested functionalities, such as hyperlinks to term definitions and to the ONC Consumer Guide of the PHR Model Privacy Notice. Therefore, ONC recommends that PHR companies primarily display the HTML version PHR Privacy Notice on their website. The PDF version of the company's PHR Privacy Notice is to be a printable version of the notice. Instruction for handling the PDF version of the company's PHR Privacy Notice is explained in the next section.

The uniformity among PHR Privacy Notices is vital to allow customers to easily compare various PHRs without causing confusion or instilling bias. In addition, the language in the PHR Model Privacy Notice template was created using consumer tested language. Therefore, ONC urges PHR company not to alter the HTML code to their notice in a way that alters the appearance, text, or functionalities of the notice generated on http://healthit.hhs.gov/PHR_Privacy. The only programming that should be done by the PHR company, outside of placing the notice on the PHR company's website, is to link the PDF version of the notice to the company's HTML-based PHR 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		We release...	Personal Data	Statistical Data
Do we release your PHR Data for these purposes?	[Yes/No]			
Do we require Limiting Agreements that restrict what third parties can do with your Personal Data ?	[Yes/No/NA]	For marketing and advertising	[Yes/No]	[Yes/No]
Do we stop releasing your Personal Data if you close or transfer your PHR?	[Yes/No/NA]	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]

Secure	
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.	
Do we store PHR Data in the U.S. only ?	[Yes/No]
Do we keep PHR Data activity logs for your review?	[Yes/No]

2. Providing a printable version of the company's PHR Privacy Notice

ONC's intent is to provide consumers a printable tool for side-by-side comparisons of PHRs. The PDF version of the company's Privacy Notice is the printable version. http://healthit.hhs.gov/PHR_Privacy will automatically generate a hyperlink from the HTML version of the company's PHR Privacy Notice to the PDF version of the company's PHR Privacy Notice in the upper right corner of the HTML-based notice. ONC strongly recommends that PHR companies not disable this hyperlink to the PDF version from the HTML-based notice.

3. Incoming Link location on PHR company website

When displaying the company's PHR Privacy Notice on the company's website, the company should place the incoming link to the notice prominently on the company's home page. If the company has multiple types of PHRs, the company's PHR Privacy Notice for each PHR type should be displayed prominently on the company's home page. This link(s) should be within the main navigation of the page, either horizontally across the top or vertically down the left-hand side. If the company banner is along the top of the webpage, the company's PHR Privacy Notice link(s) should be above the banner. The link(s) can be either at the top left, top center, or top right of the page and should be labeled "PHR Privacy Notice." This incoming link(s) to the company's PHR Privacy Notice should NOT be placed at the bottom of company's website. The name of the link cannot be modified or added to. The labeling of this link should contain size 10 font or above so that customers can easily find the link to the PHR Privacy Notice. The font color on the link(s) can be consistent with the site design, but provide contrast to the background color such that the link(s) can be easily identified by site users.

4. Browser Window for the PHR Model Privacy Notice

When adding a link to the PHR Privacy Notice from anywhere on your company web site, it is important to note that the Notice should open in a new browser window. The HTML code for this action should be: ``. This code will force the PHR Privacy Notice to open in a new browser window.

5. Information entered on http://healthit.hhs.gov/PHR_Privacy is not retained

ONC does not retain copies of generated notices or retain information entered by the PHR company to generate this notice at

http://healthit.hhs.gov/PHR_Privacy. All information will be lost after navigating away from the http://healthit.hhs.gov/PHR_Privacy. Therefore, PHR companies must download and save their generated company specific PHR Privacy Notice before leaving http://healthit.hhs.gov/PHR_Privacy.

6. Updating company PHR Privacy Notice if company policies have changed

If a PHR company must update their PHR Privacy Notice due to a change in company policy, they should go to http://healthit.hhs.gov/PHR_Privacy to generate a new notice. We strongly recommend that PHR companies do not update their company specific notice by altering the XML-based code of the original company specific PHR Privacy Notice. The reason for this is because http://healthit.hhs.gov/PHR_Privacy has been programmed to automatically generate answers in the notice based on information the PHR company entered for the previous question in the notice. For example, the answer to “Do we release your PHR Data for these purposes for these purposes?” is automatically by http://healthit.hhs.gov/PHR_Privacy based on the PHR company’s answers submitted for the yellow table.