



Collaboration of the Health IT Policy and Standards Committees

Policy and Standards Federal Advisory Committees on Health Information Technology to the National Coordinator

Consumer Task Force

Donna Cryer, co-chair
Patty Sengstack, co-chair

October 5, 2016



Membership

Member	Organization	Role
Donna Cryer	Global Liver Institute	Co-Chair
Patricia Sengstack	Bon Secours Health System	Co-Chair
Brian Ahier	Medicity	Member
Susan Brown	Telligen	Member
Mark Savage	National Partnership for Women & Families	Member
Kevin Fowler	Kidney Health Initiative	Member
Leslie Kelly Hall	Healthwise	Member
Susan Hull	Cincinnati Children's Hospital Medical Center	Member
George Mathew	ActiveHealth Management/Aetna	Member
Carolyn Kerrigan	Dartmouth-Hitchcock Medical Center	Member
John Derr	JD & Associates Enterprises, Inc.	Member
Angela Kennedy	Louisiana Tech University	Member
<i>Margeaux Akazawa</i>	<i>HHS</i>	<i>ONC Lead</i>

Charge

- Convened on an as needed basis, the task force will provide insight on ONC/HHS projects/initiatives with a consumer focus to ensure the person remains at the center, engaging the experience and feedback of both patients and providers.
 - » Focus: The Task force will be charged with providing feedback on the Model Privacy Notice and deliverables around [Patient-Generated Health Data](#) (PGHD)

Model Privacy Notice

Model Privacy Notice – Background

- Model Privacy Notice: a voluntary, openly available resource designed to help developers provide transparent notice to consumers about what happens to their data.
- The MPN's approach is to provide a standardized, easy-to-use framework to help developers clearly convey information about privacy and security to their users.
- The 2011 version of the MPN was developed in collaboration with the Federal Trade Commission and focused on Personal Health Records (PHRs), which were the emerging technology at the time.

2011 Model Privacy Notice for PHRs Template

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



Consumer Guide

Use this page to understand how [Company Name] and our [service providers](#) release and secure your [PHR Data](#).

Release			Personal Data	Statistical Data
Do we release your PHR Data for these purposes?	[Yes/No]	We release...		
		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]
Do we require Limiting Agreements that restrict what third parties can do with your Personal Data?	[Yes/No]			
Do we stop releasing your Personal Data if you close or transfer your PHR?	[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]			

<https://www.healthit.gov/sites/default/files/phr-model-privacy-notice-final-2011.pdf>

2016 Update to the Model Privacy Notice

- Modernize the MPN to be a more useful resource for consumers and developers in a market with more varied products that are collecting different digital health information.
- ONC put out a request for information on March 1, 2016 and [sought comment](#) on what information practices health technology developers should disclose to consumers and what language should be used to describe those practices.
- The public comment period closed on April 15, 2016. We received 13 submissions with broad stakeholder representation - from developer organizations representing over 5,100 members, provider organizations representing over 200,000 providers, and consumer organizations representing patients and consumers across the country.
 - » The public comments are posted [here](#).

Federal Register Notice for the 2016 Model Privacy Notice

1. **User scope:** What types of health technology developers, including non-covered entities and potentially HIPAA-covered entities, could and should use an updated voluntary MPN?
2. **Information Type:** What information types should be considered in and out of scope for the MPN?
3. **Information Practices:** What types of practices involving the information types listed in Question 2 above should be included in the MPN?
4. **Sharing and Storage:** What privacy and security issues are consumers most concerned about when their information is being collected, stored, or shared?
5. **Security and Encryption:** What information should the MPN convey to the consumer regarding specific security practices, and what level of detail is appropriate for a consumer to understand?
6. **Access to other device information:** What types of information that an application is able to access on a consumer's smartphone or computer should be disclosed?
7. **Format:** How should the MPN describe practices about the format in which consumer information is stored or transmitted (*e.g.*, individually identifiable or de-identified, aggregate, or anonymized), particularly when their information is being shared with, or sold to, third parties? How should anonymized or de-identified information be defined for the purposes of the MPN?
8. **Information portability:** How should the MPN describe to consumers whether an application enables the consumer to download or transmit their health information?

Model Privacy Notice- Task Force Homework

1. Is the MPN language clear and are terms understandable to consumers? If not, what suggestions do you have to make the content more consumer-friendly and easier to understand?
2. What are consumers' primary concerns with privacy and security of their data when using health apps or devices? Are there any concerns that are missing from this draft notice template?
3. How can we simplify the notice?
4. Does the draft content provide enough detail on privacy and security terms for consumers to understand? If not, what additional details or definitions should be included?

Model Privacy Notice Overall Feedback

- Overall members felt the Model Privacy Notice was clear, simple, and well done.
- Members identified certain terms and items that could use additional definition, plain-language replacements, or a hyperlink to additional information.
- Members suggested that the tone of the notice could be more conversational.
- Members recommended a drop-down format that would allow for consumers who wish to learn more to get more details while keeping the notice simple.
- Members discussed how clear the two categories of data, identifiable vs. de-identifiable/aggregate, and the terms privacy vs. security would be to consumers. Members recommend not only indicate the difference between the terms but what happens in certain scenarios, consequences of those scenarios, and how a consumer can get more information.

Model Privacy Notice Feedback- Language Clarity

Is the MPN language clear and are terms understandable to consumers? If not, what suggestions do you have to make the content more consumer-friendly and easier to understand?

- Members overall thought the language was about as clear and appropriate as it can be for the average consumer.
- A member found that jumping back between the terms “we” (developer) and “you” (user) may confuse consumers. Suggest including clear specification of the developer’s name and name of the app or technology or drafting the template with a blank (“__”) where the developer could use their name to reduce confusion.
- A member suggested that “Use” and “sharing” of data may confuse consumers as they may not know the difference between the two.
- Suggest that the MPN be available in at least 15 languages nationally and be accessible to people of various disabilities.

What are consumers' primary concerns with privacy and security of their data when using health apps or devices?

- Members noted that when it comes to privacy and security of their data, consumers are primarily concerned with:
 - » Their identity and what information is tied to their identity
 - » Where data is going, how it is being used, and if it will be used against them
 - » Who can see their data
 - » Protections to the data in the case of a breach or a hack and who they can contact if their information is hacked
 - » Unexpected uses of data or surprise omissions
 - » What happens to information stored and how long is it kept?

Model Privacy Notice Feedback- Consumers' Concerns with Privacy and Security, continued

Are there any concerns that are missing from this draft notice template?

- Members identified the following points that should be included or edited in the Draft MPN content to better address consumers' concerns with the privacy and security of their data:
 - » **Information portability:** the notice should disclose whether the device or technology allows for information portability whenever the consumers wants and whether it allows the consumer to download and share all data, including data contributed by the consumer as well as data incorporated from other sources, perhaps automatically
 - » **Usability:** access, edit, and deleting are distinct functions. They should be treated separately.
 - » **Identifiable vs. De-identified data:** A member noted that consumers are primarily concerned with information that is tied to their identity and are less concerned with de-identified information. The template's "How we Share Your Information" section should be clearer that the information is tied to the individual while the second should focus more on ensuring the consumer that there are no loopholes in using de-identified data.
 - » **Scope:** The MPN's scope (what the MPN covers) and what is collected (details of the information collected as separate from how the information is used) should be clearer in the MPN template

Model Privacy Notice Feedback- How to Simplify the Notice

How can we simplify the notice?

- Overall, members thought the draft notice was simple enough.
- Areas to simplify*:

Term/Section	Suggestion
Four bullet points under “use of data” section (marketing/research/company reporting/ developing software)	No need to repeat the four bullet points. Could be stated once in a footnote and referenced in each cell where appropriate.
“You can share the data” section is confusing as it includes a disclaimer.	The checklist in this section does not add value. If you keep the checklist, suggest editing to say “we strongly recommend you do NOT share this data with _____ (social media, for example)”

**Note: This list is not exhaustive of members’ comments as several members provided in-text edits to simplify the draft content*

Does the draft content provide enough detail on privacy and security terms for consumers to understand? If not, what additional details or definitions should be included?

- Members recognized the balance between too much detail and not enough when it comes to privacy and security terms
- Members suggested the following be added to the notice:
 - Use hyperlinks or info-buttons to provide additional details on terms for consumers who seek it.
 - More details on the scope of the MPN and what data the technology collects
 - Include information so that consumer are legally assured that they are the clear owner of their PHR and if an entity, with permission, on behalf of the consumer, requests the PHR or any of its person identified information it has to be in a standardized format (in C-CDA format) and they must comply.

Workplan

Meeting Dates	Task
Thursday, September 8 th at 1:00pm	<ul style="list-style-type: none"> ✓ Feedback on Committee Presentation ✓ Model Privacy Notice overview and homework
<i>Tuesday, September 13th – Joint Committee Meeting</i>	<ul style="list-style-type: none"> ✓ Share feedback with Joint Committee
Tuesday, September 27 th at 1:00pm	<ul style="list-style-type: none"> ✓ Model Privacy Notice feedback
Tuesday, October 11 th at 1:00pm	<ul style="list-style-type: none"> • Tentative – Playbook overview
Monday, October 17 th at 2:00pm	<ul style="list-style-type: none"> • Patient generated health data (PGHD) presentation
Wednesday, November 9 th at 1:00pm	<ul style="list-style-type: none"> • PGHD feedback
Monday, November 21 st at 2:00pm	<ul style="list-style-type: none"> • PGHD feedback
Thursday, December 1 st at 1:00pm	<ul style="list-style-type: none"> • PGHD feedback
Wednesday, December 14 th at 2:00pm	<ul style="list-style-type: none"> • PGHD feedback



Collaboration of the Health IT Policy and Standards Committees

Policy and Standards Federal Advisory Committees on Health Information Technology to the National Coordinator



Consumer Task Force

Donna Cryer, co-chair
Patty Sengstack, co-chair