



The Office of the National Coordinator for
Health Information Technology

ONC Privacy Policy Snapshot Challenge

Q&A Webinar
January 12, 2017





On Today's Call

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Agenda:

- Introduction
- Model Privacy Notice
- Privacy Policy Snapshot Challenge Goals
- Challenge Details
- Q & A



Office of the National Coordinator of Health IT (ONC)

- The Office of the National Coordinator for Health Information Technology (ONC) is at the forefront of the administration's health IT efforts and is a resource to the entire health system to support the adoption of health information technology and the promotion of nationwide health information exchange to improve health care.
- ONC is organizationally located within the Office of the Secretary for the U.S. Department of Health and Human Services (HHS).
- ONC is the principal federal entity charged with coordination of nationwide efforts to implement and use the most advanced health information technology and the electronic exchange of health information



ONC Prize Challenges

- Better health, better care, better value through quality improvement
- Spotlight areas of high interest to ONC and HHS
- Direct attention to new market opportunities
- Continue work with start-up community and administer challenge contests
- Increase awareness and uptake of new standards and data



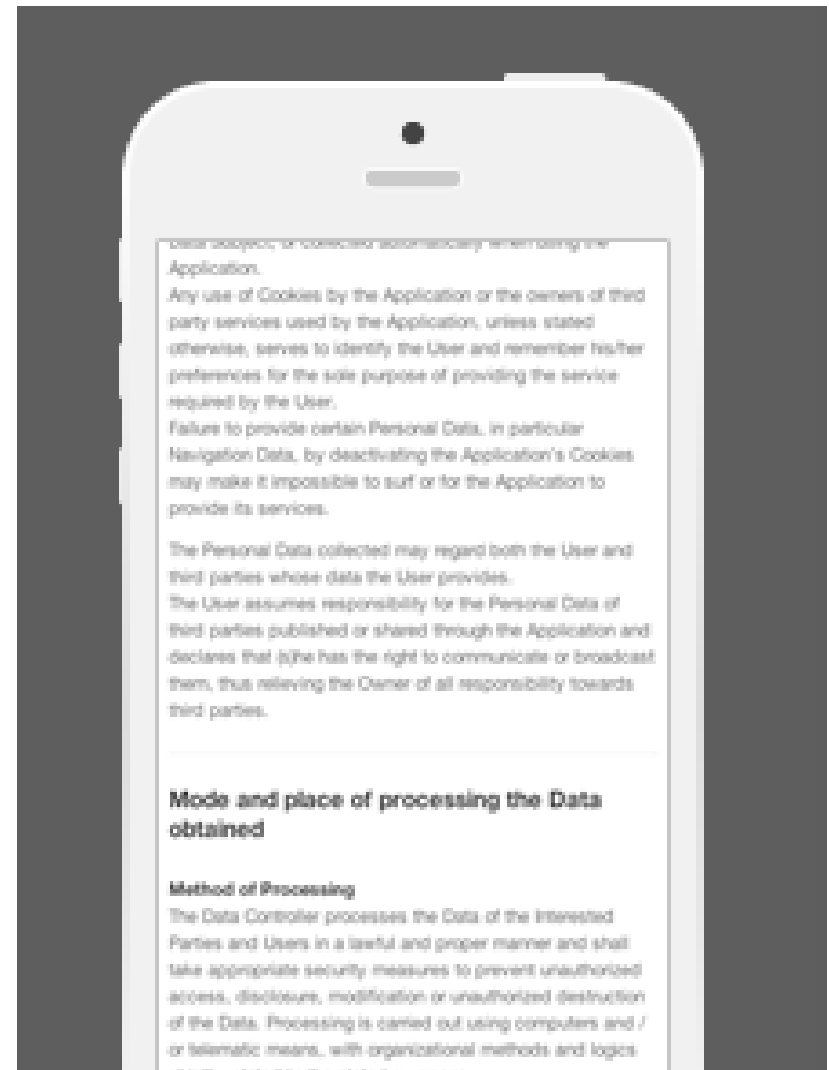
Model Privacy Notice - Background

- Model Privacy Notice (MPN): 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.



Current Landscape

- There is now a broad range of consumer health technologies beyond PHRs.
- More and more individuals are obtaining access to their electronic health information and using consumer health technology to manage this information.
- Users are concerned about privacy and security of their data.
- Existing privacy policies are long, complex, and confusing.
- Very few users read the privacy policy and those that do may not fully understand the content in the policy.





An Updated MPN

What if...

- ... Privacy practices were as easy to understand as a nutrition label?
- ... Users were provided with a snapshot of the privacy practices that they are most concerned about in terms that they understand?





Steps to Update the MPN

- 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.
- Further engage stakeholders, including our federal advisory committees, federal partners, privacy organizations, developers and developer associations, and, of course, consumers.
- Incorporate stakeholder feedback in drafting MPN content.

ONC's 2016 Model Privacy Notice (MPN)

Tech Developer Preamble

Preamble for Health Technology Developers	
What is the Model Privacy Notice (MPN)?	The MPN is a voluntary, openly available resource to help health technology developers who collect digital health data clearly convey information about their privacy policies to their users. Similar to a nutritional label, the MPN provides a snapshot of a company's existing privacy and security policies to encourage transparency and help consumers make informed choices when selecting products. The MPN does not mandate specific policies or substitute for more comprehensive or detailed privacy policies.
Who is the MPN for?	The MPN is for health technology developers whose technology or app uses and/or shares users' health data ¹ .
What laws might apply to you?	Health technology developers should consult the Federal Trade Commission (FTC)'s Mobile Health Apps Interactive Tool (which was developed in conjunction with the following Department of Health and Human Services offices and agency: ONC, Office for Civil Rights (OCR), and the Food and Drug Administration (FDA)) to determine if they need to comply with the FTC Act, the FTC's Health Breach Notification Rule, HHS's Health Insurance Portability and Accountability Act (HIPAA) Privacy, Security and Breach Notification Rules, or FDA rules implementing the Federal Food, Drug & Cosmetic Act, as applicable. This tool is not meant to be legal advice about all compliance obligations, but identifies relevant laws and regulations from these three federal agencies.
Does use of this MPN satisfy HIPAA requirements to provide a notice of privacy practices?	No. The MPN does not ensure compliance with HIPAA or any other law. However, the MPN may be used, as applicable, in conjunction with a HIPAA notice of privacy practices (please see MPN). To find more information on HIPAA directed towards health technology developers, visit the HIPAA Q's Portal for Health App Developers .

ONC's 2016 Model Privacy Notice (MPN)

Draft Content

As of December 2, 2016

Note: Developers of consumer health technology or apps (“health technology developers”) that collect digital health data about individuals would use this template to disclose to consumers the developer’s privacy and security policies. “**We**” refers to the health technology developer or technology product and “**you/your**” refers to the user/consumer of the health technology. For all endnotes provided in the MPN, the information specified in the endnote is required to be included in the privacy notice. However, for purposes of the Challenge, flexibility is permitted for how the information is presented (e.g., use of a link or pop up box) as long as the format maintains clear interfaces.

***Directions for the health technology developer:** If the health technology developer is a HIPAA covered entity, select one of the following statements to be inserted in the privacy notice:

Option 1: Please note that the health data we collect as part of this [insert name of technology product] are not protected by HIPAA and our company’s HIPAA Notice of Privacy Practices does not apply.

Option 2: Some of the health data we collect as part of this [insert name of technology product] also are protected by HIPAA. Read our HIPAA Notice of Privacy Practices (embed link or popup) for more information.

ONC's 2016 Model Privacy Notice (MPN)

Use: How we use your data internally
We collect and use your identifiable data ² : <ul style="list-style-type: none"><input type="checkbox"/> To provide the primary service³ of the app or technology<input type="checkbox"/> To develop marketing materials for our products<input type="checkbox"/> To conduct scientific research<input type="checkbox"/> For company operations (e.g., quality control or fraud detection)<input type="checkbox"/> To develop and improve new and current products and services (e.g., analytics⁴)<input type="checkbox"/> Other: _____
Share: How we share your data externally with other companies or entities
We share your identifiable data ⁵ : <ul style="list-style-type: none"><input type="checkbox"/> To provide the primary service⁶ of the app or technology<input type="checkbox"/> To conduct scientific research<input type="checkbox"/> For company operations (e.g. quality control or fraud detection)<input type="checkbox"/> To develop and improve new and current products and services (e.g., analytics⁷)<input type="checkbox"/> Other: _____<input type="checkbox"/> We DO NOT share your identifiable data⁸
We share your data AFTER removing identifiers (note that remaining data may not be anonymous) : <ul style="list-style-type: none"><input type="checkbox"/> For the primary purposes of the app or technology<input type="checkbox"/> To conduct scientific research<input type="checkbox"/> For company operations (e.g., quality control, fraud detection)<input type="checkbox"/> To develop and improve new and current products and services (e.g., analytics⁹)<input type="checkbox"/> Other: _____<input type="checkbox"/> We DO NOT share your data after removing identifiers



ONC's 2016 Model Privacy Notice (MPN)

Sell: Who we sell your data to	
We sell your identifiable data ¹⁰ to data brokers ¹¹ , marketing, advertising networks, or analytics firms.	<input type="checkbox"/> Yes <input type="checkbox"/> Yes; only with your permission ¹² <input type="checkbox"/> No
We sell your data AFTER removing identifiers (note that remaining data may not be anonymous) to data brokers ¹³ , marketing, advertising networks, or analytics firms.	<input type="checkbox"/> Yes <input type="checkbox"/> Yes; only with your permission ¹⁴ <input type="checkbox"/> No
Store: How we store your data	
Are your data stored on the device?	Yes / No
Are your data stored outside the device at our company or through a third party?	Yes / No
Encryption: How we encrypt your data	
Does the app or technology use encryption ¹⁵ to...	
encrypt your data in the device or app?	<input type="checkbox"/> Yes, by default <input type="checkbox"/> Yes, when you take certain steps (click to learn how) <input type="checkbox"/> No <input type="checkbox"/> N/A
encrypt your data when stored on our company servers or with an outside cloud computing ¹⁶ services provider?	<input type="checkbox"/> Yes, by default <input type="checkbox"/> Yes, when you take certain steps (click to learn how) <input type="checkbox"/> No <input type="checkbox"/> N/A
encrypt your data while it is transmitted?	<input type="checkbox"/> Yes, by default <input type="checkbox"/> Yes, when you take certain steps (click to learn how) <input type="checkbox"/> No <input type="checkbox"/> N/A
Privacy: How this technology accesses other data	
Will this technology or app request access to other device data or applications, such as your phone's camera, photos, or contacts?	<input type="checkbox"/> Yes, only with your permission. It connects to... <ul style="list-style-type: none"> <input type="checkbox"/> Camera <input type="checkbox"/> Photos <input type="checkbox"/> Contacts <input type="checkbox"/> Location services <input type="checkbox"/> Microphone <input type="checkbox"/> Health monitoring devices <input type="checkbox"/> Other: _____ <input type="checkbox"/> [If yes] Here is how you can check your settings, including permissions set as a default...No
Does this technology or app allow you to share the collected data with your social media accounts, like Facebook?	<input type="checkbox"/> Yes <input type="checkbox"/> Yes, only with your permission. <input type="checkbox"/> [If yes] Here is how you can check your settings...No

ONC's 2016 Model Privacy Notice (MPN)

User Options: What you can do with the data that we collect	
Can you access, edit, share, or delete the data we have about you?	<input type="checkbox"/> Yes. You can... <ul style="list-style-type: none"> <input type="checkbox"/> Access your data <input type="checkbox"/> Edit your data <input type="checkbox"/> Share your data <input type="checkbox"/> Delete your data [If yes] Here is how to do this... <input type="checkbox"/> No
Deactivation¹⁷: What happens to your data when your account is deactivated	
When your account is deactivated/terminated by you or the company, your data are...	<input type="checkbox"/> Deleted immediately <input type="checkbox"/> Deleted after x years <input type="checkbox"/> Permanently retained and used <input type="checkbox"/> Retained and used until you request deletion
Policy Changes: How we will notify you if our privacy policy changes	
<i>Describe how/if the company will notify consumers of privacy policy changes (e.g. merger or acquisition) and provide link to section in privacy policy.</i>	
Breach¹⁸: How we will notify you and protect your data in case of an improper disclosure	
<i>(Company name) complies with all applicable laws regarding breaches. Describe how the company will protect consumers' data in the case of a breach and provide link to section in privacy policy.</i>	
Contact Us	
[Legal Entity Name]	
[Link to full privacy policy]	
[Link to Online Comment/Contact Form]	
[Email Address]	
[Phone Number]	
[Address; minimum, Country]	

ONC's 2016 Model Privacy Notice (MPN)

Endnotes

- The endnotes provide definitions and additional information for terms in the draft content.
- For all endnotes, the information specified in the endnote is required to be included in the MPN generator however flexibility is permitted on how the information is presented as long as the format maintains a clear interface.
- For the following terms, a more consumer-friendly definition may be substituted. Such substitution can be developed based on consumer testing:
 - Analytics
 - Encryption
 - Cloud Computing
 - Deactivation



Privacy Policy Snapshot Challenge

- The Privacy Policy Snapshot Challenge calls upon developers, designers, health data privacy experts, and creative, out-of-the-box thinkers to use [ONC's Model Privacy Notice template](#) to create an online tool that can generate a user-friendly “snapshot” of a product’s privacy practices.
- The MPN must be customizable to reflect the app or technology’s particular data privacy and use policies.
- Inform and educate the user so that they understand how the app or technology uses their personal health data.
- Test with consumers to bring in direct user feedback.



Submission Components

- Framework, library, or plugin file(s) for the MPN generator.
- ReadMe file that documents usage and installation instructions and system requirements (including supported browsers).
- Link to a demo webpage of the MPN generator.
- Slide deck of no more than 10 slides that describes how the submission functions, addresses the application requirements, and includes evidence of consumer testing of the customizable MPN with a minimum of 5 people.
- YouTube or Vimeo link to a video demo (5 minute max) showing implementation and use of the MPN generator and creation of the customizable MPN, and may also address consumer testing.
- Link to a Github Repository that includes the submission elements above. Submitters can make the Repository private so that their code is not out in the open during the submission and review phase, but are required to make it public if designated as challenge winners.



Evaluation Criteria

- Accurate use of Model Privacy Notice content, including appropriate modification of flexible language and no deviation from standardized language.
- Use and demonstration of best practices in developing and presenting web content for consumption, including consumer testing, web design, and accessibility, as exemplified in the resources provided above.
- Visual appeal of the generated MPN.
- Ease of use for a developer to implement and use the MPN generator, including ability to customize the MPN.



Prizes

First Place

\$20,000

Second Place

\$10,000

Third Place

\$5,000

Plus visibility, prestige, and recognition!



Timeline

Challenge Launch

December 13, 2016

Submissions Due

April 10, 2017

Winner Announcement

May-June, 2017



How to Apply

- ✓ Go to <https://www.challenge.gov/challenge/privacy-policy-snapshot-challenge/>
- ✓ Click “Submit Solution”
- ✓ Enter the Required Fields
- ✓ Upload Files
- ✓ Agree to Terms and Conditions
- ✓ Submit Solution

The screenshot shows the 'Privacy Policy Snapshot Challenge' page on the challenge.gov website. The page is titled 'Privacy Policy Snapshot Challenge' and is hosted by the Department of Health and Human Services. It includes an 'About the Challenge' section, a 'Prizes' section, and a 'Challenge Details' sidebar.

Department of Health and Human Services

Privacy Policy Snapshot Challenge

About the Challenge

Help consumers learn how apps use patient health data!

Posted By: Department of Health and Human Services
 Category: Software/Apps
 Skill: Software/Apps
 Interest: Health

Submission Dates: 12 p.m. ET, Dec 13, 2016 - 2 p.m. ET, Apr 10, 2017

SUMMARY: The Privacy Policy Snapshot Challenge is a call for designers, developers, and health data privacy experts to create an online Model Privacy Notice (MPN) generator. The MPN is a voluntary, openly available resource designed to help health technology developers who collect digital health data clearly convey information about their privacy and security policies to their users. Similar to a nutrition facts label, the MPN provides a snapshot of a product's existing privacy practices, encouraging transparency and helping consumers make informed choices when selecting products. The MPN does not mandate specific policies or substitute for more comprehensive or detailed privacy policies.

Sign up for the informational and Q&A webinar on Thursday, January 12 at 2:00 pm ET

In 2011, the Office of the National Coordinator for Health Information Technology (ONC) collaborated with the Federal Trade Commission (FTC) and released a Model Privacy Notice focused on personal health records (PHRs), which were the emerging technology at the time (view 2011 PHR MPN). The project's goals were to increase consumers' awareness of companies' PHR data practices and empower consumers by providing them with an easy way to compare the data practices of two or more PHR

Prizes

- First Place**
\$20,000.00
- Second Place**
\$10,000.00
- Third Place**
\$5,000.00

Challenge Details

- Discussions 2
- Solutions 0
- Rules
- Submit Solution
- Challenge Followers 8

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Solomon Powell:
Are the submitted solutions



Recap and Reminders

- The Privacy Policy Snapshot Challenge is a **design challenge**
- ONC's Model Privacy Notice draft content was developed through stakeholder feedback
- Remember to...
 - Review the MPN draft content (including endnotes)
 - Some definitions are modifiable
 - Test your solution with at least 5 people



Links and Resources

- Challenge Details and Submission
 - <https://www.challenge.gov/challenge/privacy-policy-snapshot-challenge>
 - Or search for “Privacy Policy Snapshot” on Challenge.gov
- Download the MPN:
 - https://www.healthit.gov/sites/default/files/2016_model_privacy_notice.pdf
- More MPN information
 - <https://www.healthit.gov/policy-researchers-implementers/model-privacy-notice-mpn>

Questions?

Email Josh Shapiro, jshapiro@capconcorp.com

Or post a comment on the challenge forum