2016 Updated Model Privacy Notice

Draft Content for Public Comment

Background

ONC is embarking on an effort to update the <u>Model Privacy Notice</u> - a voluntary, openly available resource designed to help developers provide transparent notice to consumers about information practices in an understandable way.

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. Similar to the FDA Nutrition Facts Label, the MPN's approach does not mandate specific policies. Instead, it helps encourage transparency of key product facts that can empower individuals to make informed choices. It is intended to focus only on some important information and does not substitute for more comprehensive privacy policies.

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. In 2016, we want to make it a more useful resource for consumers and developers in a market with more varied products that are collecting digital health information, such as mobile applications (apps) and wearable devices.

Updated MPN Draft Content for Public Comment

ONC drafted content for an updated MPN template based on feedback from public comment submitted through a request for information on March 1, 2016. The public comments are posted <u>here</u>.

Privacy and security is a complex topic and we want to ensure that the MPN is **understandable and engaging from a consumer's point of view** and also addresses consumers' concerns around privacy and security of their health information.

We are requesting **consumer-focused input** on the draft content to make the MPN clear, simple, and user-friendly. Public comment on the draft is open until **September 15th, 2016.** Email feedback by this date to <u>faca-onc@altarum.org</u>.

2016 Updated Model Privacy Notice Draft Content for Public Comment

Note: This is draft content for a Model Privacy Notice template. The health technology developer would populate this template with information regarding their company's privacy and security policies. "We" refers to the health technology developer and "you/your" refers to the user/consumer of the health technology.

Date Last Updated: 9/7/2016

How we use your information	
Identifiable/ personal information:	We collect and use this kind of data for:
Identifiable health and personal information	Marketing and advertising
includes demographic information, any	Medical and pharmaceutical research
information regarding your physical or mental	□ For reporting about our company and our
health conditions and health care, and any	customer activity
information that could be used to identify you,	□ For developing software applications
such as your IP address.	
Aggregate, statistical, or de-identified data	We collect and use this kind of data for:
This data removes individual identifiers so that the	Marketing and advertising
data no longer identifies you.	Medical and pharmaceutical research
	For reporting about our company and our
	customer activity
	For developing software applications
How we share your information	
Identifiable/ personal information:	We share this kind of data for:
Identifiable health and personal information	Marketing and advertising
includes demographic information, any	Medical and pharmaceutical research
information regarding your physical or mental	For reporting about our company and our
health conditions and health care, and any	customer activity
information that could be used to identify you,	With your insurer and employer
such as your IP address.	Sale of data
Aggregate, statistical, or de-identified data	We share this kind of data for:
This data removes individual identifiers so that the	Marketing and advertising
data no longer identifies you.	Medical and pharmaceutical research
	For reporting about our company and our
	customer activity
	With your insurer and employer
	Sale of data
How we store your information	
Is your data stored locally in the device or app?	Yes / No
Is your data stored externally, for example by the	Yes / No
company servers or a third party cloud service provider?	
Is the data stored outside the US?	Yes/ No

How we protect your information		
Does the technology encrypt your data?	Yes/No	
	[If yes] For more information on our information	
	security practices, see [link to privacy policy]	
How this technology accesses other device data		
Does this technology access other device data or	Yes/No	
applications, such as your phone's camera, photos,	[If yes] Here is how you can check your settings	
geo-location, or contacts?		
Can this technology connect to your social media	Yes/No	
accounts, like Facebook?	[If yes] Here is how you can check your settings	
What can you do with the data that we collect?		
You can access, edit, or delete the information we	Yes/No	
have about you.	[if yes] Here is how to do this.	
You can share the data we collect.	Yes/No	
	[If yes] Once you obtain your information, you can	
	do anything you want with it. However, it's	
	important to make the decision to send your	
	information carefully – and that you understand	
	the privacy and security risks of sharing it with	
	others.	
	You can share your data with:	
	Friends and family	
	Doctors and providers	
	Social media	
	□ Other	
	Here is how you do this	
What happens to your data when you	When you deactivate/cancel your account, your	
deactivate/terminate your account?	data	
How will we notify you and protect your information in case of a breach or criminal activity?		
Describe how the company will protect information in the case of a breach and provide link to section in privacy		
policy.		
How will we notify you if our privacy policy changes?		
Describe how/if the company will notify consumers of privacy policy changes and provide link to section in privacy		
policy.		
How Can You Contact Us With Questions?		
[Mailing Address]		
[Phone Number]		
[Email Address]		
[Link to Online Comment/Contact Form]		
[Link to full privacy policy]		