

April 15, 2016

Dr. Karen DeSalvo, M.D., M.P.H., M.Sc.  
National Coordinator for Health Information Technology  
U.S. Department of Health and Human Services  
330 C Street SW  
Washington, D.C. 20024

**Re: Request for Information on Updates to ONC's Voluntary Personal Health Record Model Privacy Notice**

Dear National Coordinator DeSalvo:

The Consumer Partnership for eHealth (CPeH) appreciates the opportunity to comment on the Request for Information on Updates to the ONC Voluntary Personal Health Record Model Privacy Notice ("Request").<sup>1</sup> CPeH is a coalition of consumer, patient and labor organizations working at the national, state and local levels to advance private and secure electronic health information exchange (health IT) in ways that measurably improve the lives of individuals and families. Led by the National Partnership for Women & Families, the combined membership of CPeH represents more than 127 million Americans. Consumers are eager to work with ONC to develop a Model Privacy Notice that clearly communicates companies' policies regarding how their electronic health information will be protected, shared and used.

The consumer health technology landscape has evolved greatly since ONC published the first Model Privacy Notice in 2011 and focused solely on the "web-based Personal Health Record." We now have a much expanded universe of smartphones and mobile applications (apps), devices, wearables and other consumer-facing applications that help to collect, send, manage and use one's health information.

Almost nine in ten patients nationally report that it is important to them to know how their health information is being collected and used.<sup>2</sup> The Model Privacy Notice can help, by disclosing in plain language how apps or devices use, share and protect the privacy and security of health information and helping consumers identify the app or device that best meets their needs and preferences.

Below we comment on specific sections of the Request:

- **User scope:** Broad use of the Model Privacy Notice by covered and non-covered entities alike and all types of health technology developers would be most useful to consumers.

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<sup>1</sup> The 19 organizations and members of the Consumer Partnership for eHealth, joined by others, who sign this letter do so jointly in one letter rather than send 19 separate letters. If ONC counts responses for any particular purpose, please count them as 19 responses rather than a single response.

<sup>2</sup> National Partnership for Women & Families, *Engaging Patients and Families: How Consumers Value and Use Health IT* (Dec. 2014), available at <http://www.nationalpartnership.org/research-library/health-care/HIT/engaging-patients-and-families.pdf>.

Consumers may not track technical or legal distinctions among different entities and developers when managing their health information from multiple sources.

- **Information types:** Similarly, broad coverage of identifiable health information generally would be most useful to consumers, rather than parsing information types that are in or out of scope. Consumers may not differentiate information types when managing their health information altogether. Moreover, different information types, when combined with identifiable health information, become identifiable health information as well.
- **Information practices:** We agree with the information practices or uses already included: marketing and advertising, medical or pharmaceutical research, reporting about company or customer activity, developing software applications, and release to insurers or employers. However, **we urge ONC to add the disclosure of the company's own uses** because consumer want and should be able to find the company's own uses transparently displayed as well. For simplicity, the Notice could employ the same set of information practices, whether the company uses consumers' health information itself or shares it with a third party. Also, we recommend adding sale of consumers' health information and release for public health reporting. Lastly, the Notice should disclose the company's or technology's own internal uses as well as releases to third parties.
- **Sharing and storage:** The Notice should disclose to consumers whether the device or technology stores one's health information locally and whether the company stores and retains the information on its servers. The company should also disclose whether it requires third parties with which it shares the health information to adhere to the same privacy and security policies it discloses in the Notice.
- **Information portability:** Consumers expect to be able to have and take their health information with them for whatever reason: choosing a different device or app, choosing a different provider, or the company terminates the service. The Notice should disclose whether the device or technology allows the consumer to download and share or transmit the data whenever the consumer wants.
- **Language and disability access:** To provide equal access, the Notice should be available in at least the top 15 languages nationally and accessible to people with disabilities.

Thank you once again for this opportunity to provide input on the update to the Model Privacy Notice. If you have any thoughts or questions about these comments, please contact Erin Mackay at (202) 986-2600 or [emackay@nationalpartnership.org](mailto:emackay@nationalpartnership.org).

Sincerely,

AARP  
American Association on Health and Disability

American Cancer Society Cancer Action Network  
Asian & Pacific Islander American Health Forum  
Association of Asian Pacific Community Health Organizations  
California Pan-Ethnic Health Network  
Caring from a Distance  
Center for Democracy & Technology  
Consumers' Checkbook/Center for the Study of Services  
DirectTrust  
Disability Rights Education & Defense Fund  
Genetic Alliance  
Healthwise  
Informed Medical Decisions Foundation  
National Consumers League  
National Health Law Program  
National Partnership for Women & Families  
The Children's Partnership  
The Foundation for Ichthyosis & Related Skin Types, Inc.