

ONC Consumer Preferences Feedback

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October 15, 2009

Thank you for the opportunity to comment on this important aspect of health reform.

The [Draft Requirement](#) does not adequately address Consumer preference to receive a copy of their own health records.

This consumer rights is important because they're mandated by ARRA and because they will enhance trust and participation in health information exchange as described in Section 2.0.

By being clear on consumer access to their complete health information, the Requirement will encourage a system that is not coercive or opaque to consumers.

Comment 1 - 2.0 - Consumer copy of their information per ARRA 2009

ARRA 2009 states:

H. R. 1—154

(e) ACCESS TO CERTAIN INFORMATION IN ELECTRONIC FORMAT.—

In applying section 164.524 of title 45, Code of Federal Regulations, in the case that a covered entity uses or maintains an electronic health record with respect to protected health information of an individual—

(1) the individual shall have a right to obtain from such covered entity a copy of such information in an electronic format and, if the individual chooses, to direct the covered entity to transmit such copy directly to an entity or person designated by the individual, provided that any such choice is clear, conspicuous, and specific;

Section 2.0 of the Draft Requirement should clearly and specifically address the applicability of consumer preferences and the information exchange standards in meeting the mandate for a consumer's "copy of such information in an electronic format."

Section 9.2.1.b does not clearly address the organization or entity that is to receive the consumer's copy of their health record in electronic form. The use of CD or other portable media for this purpose is slow, expensive and inconvenient compared to electronic transfer over the Internet. The Requirement should clearly address how a consumer can specify their personal computer, a secure or insecure email account or a file handling agent as the Internet destination for their health record copy.

Comment 2 - 6.4 - Voluntary Consumer Identity

Section 6.4 of the Draft Requirement pertains to consumer identity and mentions ID Cross-Referencing and NHIN Patient Discovery as a pre-requisite of preferences management. A requirement that consumers participate in regional or national directories is potentially coercive and may cause many to Op-Out just to avoid being listed in an involuntary directory.

Preference management Requirement can address this issue by mandating that Primary and Secondary Receiving Organizations accept and honor a consumer's voluntary identifier.

A voluntary identifier is one where the consumer can choose the trusted institution that will authenticate them to the health care Organization. Said trusted institution could be a state agency, bank or telecommunications carrier and may or may not be required to carry similar certification as other Organizations that participate in consumer preferences exchange.

HHS and other federal agencies have already adopted OpenID as a voluntary consumer identifier. See http://www.healthimaging.com/index.php?option=com_articles&view=article&id=18927

OpenID (or equivalent voluntary identifier) should be allowed as an electronic means of consumer authentication for the purpose of preference management.

Comment 3 - 8.1.b - Non-healthcare trust provider as Primary Receiving Organization

Section 8.1.b points out the need for positive identification of the Primary Receiving Organization relative to their role in managing consumer preference. To the extent that an organization is managing consumer preference it is acting more as trust provider than a healthcare provider. Banks, telephone companies, law firms and escrow agents are in the business of managing consumer preference and should be allowed to extend their services to health information exchange.

To avoid coercion, increase competition and enhance audit ability as described in Section 6.16 and 6.25, consumers should be allowed to choose non-healthcare providers as Primary Receiving Organizations. This will also have the benefit of facilitating compliance by solo and small group practices that wish to install a simpler EMR that delegates preference management to an independent and non-competitive entity.