Disease Registries on the Nationwide Health Information Network

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Abstract

Background:

Donation by individuals of their protected health information (PHI) for evidence-based research potentially benefits all individuals with disease through improved understandings of disease patterns. In the future, a better understanding of how disease features combine into unique patterns of disease will generate new disease classifications, supporting greater specificity in health management techniques. However, without large numbers of people who donate their PHI to disease registries designed for research, it is difficult for researchers to discover the existence of complex patterns or to create more specific evidence-based management techniques. In order to identify new opportunities in disease registry design, an analysis of the current stage of maturity of the newly created U.S. Nationwide Health Information Network (NwHIN) related to large-scale consumer donation of PHI is presented.

Methods:

Utilizing a use-case analysis methodology, the consumer-centric designs of the policies and technologies created for the NwHIN were examined for the potential to support consumer donations of PHI to research.

Results:

The NwHIN design has placed the enforcement point for the policy-based release of PHI over the Internet into a specialized gateway accessible to consumer authorization. However, current NwHIN policies leave the final decision regarding release of PHI for research to the health care providers rather than to the consumers themselves.

Conclusions:

Should disease registries designed for research be established on the NwHIN, consumers might then directly authorize the donation of their PHI to these disease registries. However, under current NwHIN policies, consumer authorization does not guarantee release of PHI by health providers.

J Diabetes Sci Technol 2011;5(3):535-542

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Abbreviations: (DURSA) Data Use and Reciprocal Support Agreement, (HIE) health information exchange, (HIO) health information organizations, (HIPAA) Health Insurance Portability and Accountability Act, (HL7) Health Level Seven, (IHE) Integrating the Healthcare Enterprise, (NHS) National Health Service, (NwHIN) Nationwide Health Information Network, (OASIS) Organization for the Advancement of Structured Information Standards, (PHI) protected health information, (SAML) security assertion markup language, (TPO) treatment, payment, or operations, (XACML) extensible access control markup language, (XML) extensible markup language

Keywords: access, consent, nationwide, personalized, privacy, registry, security

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