

## ILHIE Authority Data Security and Privacy Committee

### Briefing Summary: Policy # 6 (Panel #2) – Granularity of Patient Choice

6. Granular Sequestration. Should patients be granted the ability to sequester specific elements of their patient record from specific providers, or in the event a patient desires some data sequestered, should the entire patient record be excluded from HIE disclosure?

#### Federal Guidance

- The Federal HIPAA Privacy Rule currently provides that individuals have the right to request that a covered entity restrict use or disclosure of protected health information for treatment, payment or health care operations, disclosure to persons involved in the individual’s health care or payment for health care, or disclosure to notify family members or others about the individual’s general condition, location, or death.<sup>1</sup> A covered entity is under no obligation to agree to requests for restrictions. HIPAA currently does not grant patients a right to sequester portions of their record or to exercise “granular” partial consent options.
- HHS ONC recently issued guidance to the recipients of HIE planning grants that patients “should have choice about which providers can access their information. In addition, recipients are encouraged to develop policies and technical approaches that offer individuals more granular choice than having all or none of their information exchanged.” The proposed ONC requirement that patients enjoy granular consent options in respect of data exchanged through an HIE represents a material change to current law.
  - In its reply to the ONC, OHIT indicated that it considered such a requirement as “challenging”. OHIT noted the following concerns:
  - HIE Technical Limitations. Current HIE/EHR technologies are relatively limited in their ability to accommodate granular patient choice.<sup>2</sup> OHIT is currently benefiting from the guidance of the Strategic Healthcare IT Advanced Research Project on Security (SHARPS) at the University of Illinois on the evolution of HIE/EHR technologies and the evolution of relevant standards; such collaboration may result in the advancement of the current state of technology and standards in the course of the next 12-24 months.
  - Patient Safety Implications. Providers have voiced concerns about rendering medical diagnoses and treatment decisions on the basis of incomplete electronic medical records, or “digital Swiss cheese”. Although patient records are currently on occasion incomplete, due to restrictive Federal and State disclosure laws with respect to special categories of “sensitive” patient information and selective disclosure by patients of their medical conditions, advocates for patient safety have urged policies be adopted that encourage patient data collection while

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<sup>1</sup> 45 C.F.R. § 164.522(a).

<sup>2</sup> Lynne Dunbrack, IDC, <http://www.healthcareinfosecurity.com/interviews/tackling-hie-privacy-issues-i-1532>. Accord, Arzt, *infra* fn. 10, slide 11 (“Granular consent models may be more difficult to implement with current tools.”)

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focusing greater attention upon defining and discouraging the data's wrongful use.

- Physician Trust in Completeness of HIE. If physicians are provided medical records which are marked with a warning that additional medical information exists but is not being made available (or if the HIE records are known to be incomplete, even if not marked with a warning label), physicians will choose not to use the HIE, and order potentially duplicate tests and procedures.

*Policy Option 1 (“All-in/all-out”): If patients are granted a choice regarding participation in HIE (either “opt-in” or “opt-out”), and a patient decides not to have some data disclosed through the HIE, all of the patient’s data will be excluded from the HIE.*

*Policy Option 2 (“Granular selection”): If patients are granted a choice regarding participation in HIE (either “opt-in” or “opt-out”), each patient is allowed to sequester certain data according to one or more of the following criteria: (a) type of clinical data; (b) type of data recipient (e.g., type of provider); (c) purpose of disclosure; or (d) timing of disclosure.*

#### Research

- No academic research into the effects and/or relative merits of such alternative policies (“All-in/all-out” v. “Granular selection”) is presently known to OHIT.

#### National Adoption

“All-in/all-out”: 31 States (19 enacted; 12 pending)  
Granular selection: 10 States  
TBD: 9 States