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Patient Privacy Rights

I'm Adrian Gropper, Chief Technology Officer for Patient Privacy Rights. PPR represents a coalition of 10.3 Million people about control over the use of their health data. The lack of control has led to unwarranted risks and lack of transparency in all aspects of healthcare.

We are all reaching the limit of patience with detailed regulations and certification mandates. Four years and $24 Billion later, physicians and patients have seen costs go up and interoperability out of reach. Four years and $24 Billion later, physicians and patients have seen costs go up and interoperability still out of reach. Meaningful Use must turn away from a institutional perspective and toward a patient-centered perspective that starts with the physician-patient relationship and the real-world family care team. Our comments are in favor of increased transparency and accountability, increased access and increased security to enable the information to be available to the patient and to include, with patient consent, the patient's family caregivers.

EHR modularity is not a substitute for interoperability and can actually tend to increase the walls that define current health care silos. The modularity we seek allows the choice of information technology to be determined as part of the physician-patient relationship. The EHR certification criteria will not adequately serve the physician's responsibility to the patient if they restrict the ability of the physician to send complete data to any other destination with support for data segmentation for privacy, accounting for disclosures, decision support, and patient-centered health records. Full strength data accessibility, is a market-based alternative to detailed technology regulation. Government efforts toward the triple aim must pivot away from an institutional focus in favor of physicians and patients.

Our interoperability focus is on the Transitions of Care functionality accessible to physicians and to the Transmit component of View / Download / Transmit accessible to patients and family caregivers. EHR certification criteria must focus on complete, timely, convenient, and secure access as directed by physicians and patients with no interference from the institutions that operate certified EHR technology.

Complete information means that any information that institutions share via any interface for Treatment Payment and Operations must also be accessible under physician direction via ToC and accessible via patient direction via Transmit functionality. Complete also means that notes should be available and coding should be preserved.

Timely means that information available via TOC and V/D/T should be accessible for decision support in real-time from any source that the physician or patient chooses and not just from sources controlled by the institution that happens to control an EHR. The delays in accessibility of information via patient-directed means must be under the control of physicians so that the physician can decide what is best for her patients.

Convenient means that physician patient and caregiver authentication must allow for automation such as Single Sign-On and Delegation to staff and family caregivers via widely available technology such as OAuth and Open ID Connect. From the patient and family care-team perspective that are dealing with numerous separate patient portals, Certified EHR technology must adopt OAuth standards to enable centralized access control and authorization management based on the UMA standards.

Finally, secure interoperability requires data segmentation for privacy, the ability to respect voluntary identities for patients I cases where DS4P is not deemed adequate by the patients, convenient delegation to family caregivers without the need to share passwords or otherwise allow unlimited and unaccountable access and real-time accounting for disclosures to make it all manageable.

Behavioral Health information is of particular concern to Patient Privacy Rights. We insist that data segmentation for privacy be implemented both internal to an EHRs institution and with respect to all interfaces. Within the institution, patient preference must be assignable by the patient to a role or specific individual. For information sharing, patient data segmentation must be respected across TOC, delegated access via V/D/T and all Treatment Payment and Operations as well.

A pivot to patient and family-centered care starts with the interfaces to certified EHR technology.