CONNECTING MICHIGAN
for health and more

Description:

In the Legal and Privacy Breakout Session for the eConsent Workshop, co-facilitators Lisa Moon, PhD and Shreya Patel will discuss the balancing of Legal and Ethical concerns that accompany eConsent. This session will contemplate timely issues such as:

- **HIPAA Right of Access.** Right of Access is the right for patients have to request copies of their own medical records at little to no cost to them, and with little to no additional effort. Closely tied into this discussion will be the Center for Medicare & Medicaid Services (CMS) Patient Access mandate of the Final Rule, which is only applicable to certain federal payers at this time.
- **HIPAA Meaningful Choice**. Meaningful choice is the right patients have to dictate how their records are shared across the healthcare landscape, whether that be through providers directly, EHRs, and/or HIEs. Included in this conversation is the idea of global opt- out of HIE, as well as the benefits and challenges of accommodating a global opt out for patients.
- **Removing HIPAA Protection.** We will discuss how to safeguard protected health information (PHI) as it moves from HIPAA Covered Entities (CEs) and Business Associates (BAs) to non-HIPPA- covered, mobile applications, which are governed by the Federal Trade Commission (FTC).
- **Repurposing Health Information**. We will delve into additional areas where health information could be repurposed for a patient's benefit. For example, for matching them to certain specialists, clinical trials, social support resources, and more.
- **Methods of Coordination**. We will discuss eConsent's ability to share information across providers (in an HIE) and its distinction from Right of Access, where patients have access to their own information and can coordinate their own care across providers.

Discussion Notes

Necessity Questions
- How beneficial would eConsent be for your organization?
- In what ways could your organization benefit from eConsent?
  - To share specially protected behavioral health information?
  - To share advance care directives?
  - To share health information in additional contexts, such as research?
  - To share health information with family, friends, or other third parties?

Necessity Dialogue
- *Mixture of both paper and electronic consent in HIEs*
  - *Problem is that it is just in an "on/off" state*
  - *Not granular at this time*
- *Conversations around in advance care planning are occurring over a technological platform, but a legally binding signature cannot take place*
  - *The issue of how to move it forward if we cannot do electronic signatures*
- *Discussion on policy advocacy:*
  - *Digital signature*
  - *Virtual witness*

Patient Control Questions
- eConsent contemplates sharing health information at the direction of the patient.
  - Is it better if patients are able to have access to their own healthcare information so they can physically take their information from provider to provider?
  - Are both necessary?
  - What are the benefits and disadvantages of both?

Patient Control Dialogue
- *Data from other organizations becomes part of their chart and is utilized by the providers for patient care*
  - *The issue of whether or not that information should be shared too?*
- *What about the notes that providers take? What if patients don't like the providers notes? What if it impacts their trust? How will that influence how comprehensive the record is if providers are filtering out information?*
  - *Is the purpose of a medical record for a patient to have access, or for the providers to have access to the information at the point of care in an unfiltered way?*

Usability Questions:
- Are patients receiving the most pertinent/ helpful information by receiving their entire medical record?
  - Should it be reformatted for ease or is providing a complete transcript the only way to fulfill Right of Access?
- What are the obligations on providers and/or mobile applications to make health information easily digestible?

Usability Dialogue
- Organizations have whole teams that works on this very thing
- Consider what the display looks like if individuals can understand what thy are seeing.
- Consider consumer group testing
- "APIs to nowhere," how do we make it usable?