Health Information Exchanges and Informed Consent

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The presentation team has no conflict interest to disclose.
Health Information Exchanges

The expansion of electronic data sharing, also known as health information exchange (HIE), is expected to increase exponentially over the next decade.¹

HIEs are heralded as a key solution to the problems of low quality and high cost of health care.²
How an HIE Works

Available at: http://www.nchie.org/patients/
Health Information Exchanges in Oklahoma

Taken from the My Health Webpage:

- Reduce health care costs associated with redundant testing, hospital admissions, and emergency department visits;
- Improve care coordination during transitions between health care settings;
- Improve patients’ experience and ability to take control of their own health;
- Improve quality care for northeastern Oklahoma;
- Bring community leaders and organizations together to utilize health information in meaningful ways to improve community care.

Available at: http://www.myhealthaccessnetwork.net/
Why HIEs Have Value

• The goal of HIEs is to facilitate access to clinical data to provide more timely, efficient, and effective care.

• HIE is also useful to public health professionals to assist in the analyses of population health.

• HIEs function on economies of scale.
Yet,

• Research suggests patients have concerns about privacy and confidentiality and HIEs.³

✓ Comments and discussion about privacy range from general concerns about privacy to specific concerns about who will have access to the personal health information, what kinds of sensitive health information would be shared, and the risk of unauthorized access to the health information via security breaches.
Ethical Issues

• The combination of self-interested aims on the part of the health care system and potential negative consequences relating to patient privacy raise questions as to what type of consent model is most appropriate for HIEs.

• The issue of whether, to what extent, and how individuals should have the ability to exercise control over their health information represents one of the foremost policy challenges related to the electronic exchange of health information.⁴
Informed Consent

Informed consent is a fundamental principal of health care interventions to protect patient interests using principals of patient autonomy.
The Spectrum of Consent

**Opt out:** In an *opt-out* model, the default is for all or some pre-defined set of data (*e.g.*, labs, summary record information) to be eligible automatically for the exchange, with a provision that patients must be given the opportunity to opt out if they follow the procedures to do so.

**Opt-in:** In an *opt-in* model, the default is that no patient data are automatically made available for the electronic exchange. Patients wishing to make all, or a pre-defined set, of their information available must actively express their desire to participate.
Opting Out Model as A Nudge

- Nudging involves restricting a patient’s choice architecture to increase transaction costs to make a provider’s desired outcome the more likely consequent.\(^5\)

- In most cases, informed consent is restriction of choice architecture to steer a patient toward the best medical practice.\(^6\)

- Shared decision making occurs when there is less clarity on a best practice.\(^6\)

- Opt out models are a “nudge” because they restrict choice architecture and increase transaction costs for the patient to take an alternative course of action.

Are HIE’s a best practice for a patient independent of the risk/benefit of the alternative?
When Are Nudge’s Ethically Supportable?

• When there is a clear best practices of the medical profession to steer the patient to that provides a direct benefit to the patient.

• Is the benefit of HIE participation clear in relation to the risk of harm?

  • If it is not clear, then shared decision making is called for, which is not consistent with permissible nudging.
Conclusion

• Having a patient affirmatively opt in to HIE will help to ensure that the patient is meaningfully participating in the exchange, aware of uses, risks, and benefits that may result. Shared decision making will be realized.

• Nudging via an “opt out” consent approach raises questions about compromising patient autonomy for the sake of utilitarian aims.
References


