

CHALLENGES OF ESTABLISHING REGISTRIES: privacy

definitions

- ✦ **Electronic Health Record**
- ✦ **Electronic Medical Record**
- ✦ **Personal Health Record**
- ✦ **Disease Registry**

Data Elements

- ✻ Patient Data.
- ✻ Lab Information.
- ✻ Radiology Information.
- ✻ Medication Information.
- ✻ Clinical Information.
- ✻ Physician Order Entry Data.

Where Privacy Becomes Important

- ✿ Remote electronic monitoring of patients.
- ✿ Data sharing in patient care, public health surveillance, and health research.
- ✿ Electronic communication between and amongst patients and providers.

Privacy & Security Concerns

✿ **Commercial misuse of data**

- ✿ Use of medical data to deny or restrict insurance coverage; restrict credit or other financial benefits.
- ✿ Unsolicited marketing.

✿ **Government misuse of data**

- ✿ Use by government agencies for secondary purposes (e.g. employment).
- ✿ Use for national security, law enforcement purposes.

privacy & Security Concerns

- ✻ **Criminal misuse of data:** fraud, identity theft resulting in financial or other harm; arising from security breaches or data leakage.
- ✻ **Data quality:** Data corruption or loss.
- ✻ **Bottom Line:** *Fear of undesirable consequences*, including financial loss, loss of personal dignity, discrimination, social stigma.

privacy & Security Services Required

- ✱ Identity management services
 - ✱ Accurate identification of system users
 - ✱ Registration
 - ✱ Credential/Role definition for access
- ✱ User Support for status change management.
- ✱ User authentication services – validating users logging into system.
- ✱ Access control services – linked to credential/role definition.

privacy & security Services Required

- ✻ Consent directive management services - recording, managing, applying, logging and where required, overriding consent directives.
- ✻ Identity protection services to de-identify and re-identify of PI during storage and use of PHI.
- ✻ Encryption services for both “at rest” and “in motion” data.

privacy & Security services required

- ✿ Integrity services to ensure record integrity; possible use of digital signatures.
- ✿ Audit services to monitor access to and use of the system.
- ✿ General security-related IT services (e.g. AV, back-up, archiving data, data destruction).

Questions to Ask

- ✦ How do we
 - ✦ decide what data elements we need?
 - ✦ de-identify and re-identify personal information?
 - ✦ provide notice?
 - ✦ obtain consent?
 - ✦ permit patients to limit disclosure of data?

questions to ask

- ✦ How do we:
 - ✦ decide who gets access?
 - ✦ ensure security is addressed?
 - ✦ manage incidents?
 - ✦ allow access by the individual concerned?

Closing Thoughts

- ✿ Privacy: Not a roadblock but certainly a challenge.
- ✿ Carefully consider both technology and procedures.
- ✿ Somewhat trite but nonetheless important: Trust and confidence of patients is paramount.

Questions

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