

# **Case Study**

**Huntz Cancer Center**

# Strategic plan

Huntz Cancer Center will host a collaborative workspace where participants can come together to share documents and data. Shibboleth will permit each component organization to manage its own identities. Physicians in smaller offices and organizations will be given guest accounts at HCC. Grouper will be used to control access to the common applications

We need the participants from the multiple organizations to be able to contribute in a practical manner while satisfying legal, institutional and security requirements

# Pilot

- Use one or more studies at HCC as a pilot (“proof of concept”)
- Pilot solution should encompass all aspects of technology, processes, policy, etc.
- Need to have metrics in place to evaluate effectiveness
- Solution could become a reference implementation for others

# Legal issues

- **Federal**
  - e-Authentication
  - FDA regs
  - HSPD-12 (PIV)
- **States**
  - Privacy and other laws

# Cultural and organizational issues

- User acceptance
- Demarcation of liability
  - What about user agreements?
- How do multiple IRBs work together?
- What happens if a patient needs to be purged?

# Technical factors

- **Schema extensions (requires widespread adoption)**
- **Shibboleth**
- **Guest accounts (at HCC)**
- **Where to host the HCC infrastructure**
- **Need to aggregate data in a central repository and put some kind of friendly UI on the front**

# Security measures

- Encryption (end-to-end)
- System to system authN
- Auditing
- authZ everywhere
- Firewall

# Financial risks/gains

- HCC has to invest money in infrastructure
- If it succeeds HCC will be in a good position to win more grants
- Failure to comply with necessary regulations could result in significant loss
  - Audits
  - Spills

# How is this different?

- **Legal and regulatory requirements could involve more than one state**
- **Cultural practices may be different**
- **Some projects may require approval of more than one IRB**

# What additional technical components or functionalities are necessary or desirable to facilitate multi-CCC research trials in the near future?

- **Additional schema extensions**
- **Workflow**
- **Repository**
- **De-identification tool (for data)**
- **Firewall**
- **Data/drive scrubbing**

**What groups could be engaged by the Internet2, NMI and others to help make such a structure a reality?**

- **Vendors**
- **NIH**
- **e-Authentication**
- **HL-7**
- **Etc.**

# What legal, political, and cultural issues are likely to need careful attention before technical solutions can be put into place?

- **Contract between participants**
- **Definition of a governance process**
- **Review of all applicable laws and regulations**
  - **Any conflicts?**
  - **Highest common denominator?**

# What might the relevant HIPAA considerations be?

- Training
- Covered vs uncovered entities

**Questions?**