

Data Governance: Developments

- ◆ **Interest from various stakeholder groups:**
 - Penn Medicine Trustees Audit Committee
 - Senior IT Council
 - Institute for Biomedical Informatics
 - Cancer Center
- ◆ **Academic literature and media attention**
 - DNA-related partnerships between health systems and drugmakers raising privacy and competitive concerns
 - JAMA article based on Chicago Medical Center / Google partnership, advocating governance to address big data and privacy
- ◆ **The moving target of “deidentified” data**
- ◆ **Commercial interest in Penn’s Data**



Proposal: Approach

- ◆ Establish agreed upon Principles to guide all efforts at Penn Medicine around Data Access, Use and Disclosure
- ◆ Establish Penn Medicine's position on specific use cases, based on applying such Principles
- ◆ Identify POC of each Use Case – to operationalize the Penn Medicine position, facilitating data access consistent with this position
- ◆ Convene Data Governance Committee to oversee process of standing up governance model, to receive and review challenging questions, and to tee up to smaller group of top leadership appropriate topics and questions.



Principles for Access, Use, & Disclosure of Patient Information

Lawful Basis



- HIPAA
- State Law
- TCPA
- Non Penn Med Patients in system

Institutional Mission & Values



- Treatment
- Research
- Education
- Strategic priorities
- Ethical considerations

Trustworthiness, Accountability



- Employed by PM
- Temps, Interns, Volunteers
- Contractually affiliated
- Closely supervised
- Onsite / Offsite
- Long Term / Short Term

Risk Mitigation



- Transparency
- Minimum necessary
- Least privilege
- Identifiability
- SSNs
- Employees
- VIPs

Strong Security Controls



- Internally: Penn approved devices or services
- Externally: Penn approved environment per IS review

Documentation



- All access requests document need, sponsor, confidentiality attestation, approval
- Contracts and/or BAA's for all third parties accessing data

