MEDINFO23

8 – 12 JULY 2023 | SYDNEY, AUSTRALIA

Ethical Issues in Data Use and Governance: Adapting Past Lessons to Emerging Needs

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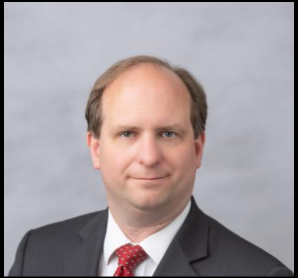
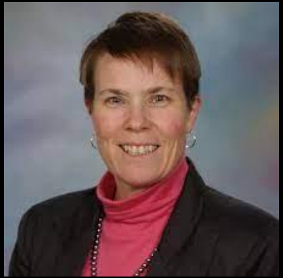
Facilitator



Dr Andrew Boyd

University of Illinois Health



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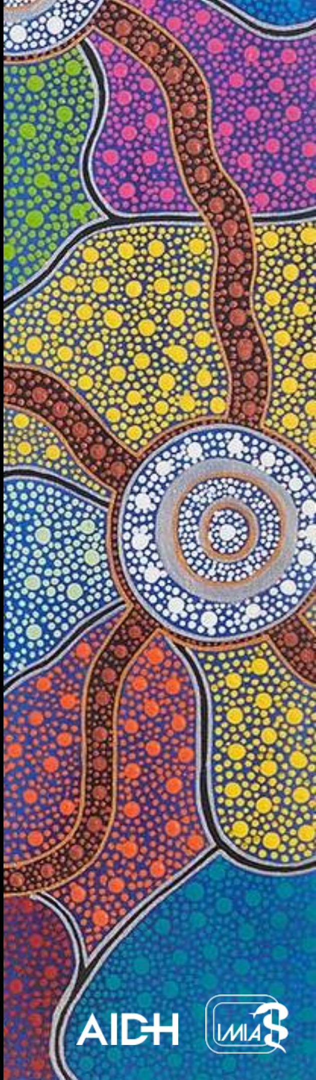

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9th July - Session 204 – 9:00 am –9:40 am AEST

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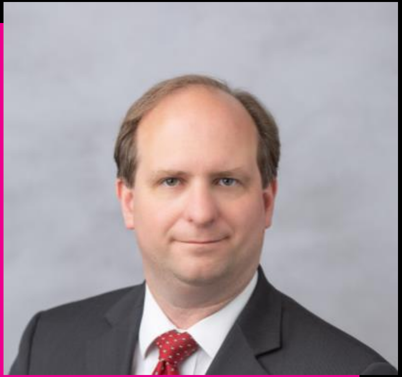

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Ethical Issues in Data Use and Governance: Adapting Past Lessons to Emerging Needs

Andrew Boyd

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Overview

- History of Ethical and Legal Concerns Health Data
- Ethical Paradigms different between countries
- Future paradigms

History of data protection

- “Data protection in health information systems : considerations and guidelines” / 1980 IMIA WG4 (217 pages)
- Commission of the European Communities DGXIII/F AIM. Data protection and confidentiality in health informatics. Amsterdam, Netherlands: IOS Press; 1991. (365 pages)
- Blobel B. Analysis, design and implementation of secure and interoperable distributed health information systems. Amsterdam, Netherlands: IOS Press; 2002.(334 pages)
  - One page of security threats and risks
- GINA (Genetic Information Non Discrimination Act)
  - US Department of Energy. Human Genome Project Information Archive: Ethical, Legal, and Social Issues 1990-2003

EHR and Genomics laws and paradigms

- Export Ban
- Signed consent for export
- Ability share with family members without patient permission
- Share all data or only actionable data
- Mutation of Indeterminant Significance

Future paradigms

- Environmental DNA
- Barriers to technology decreasing in cost
- Prioritize societal benefits versus individual benefits
- Retraining of clinicians for new interventions
- Is removing name/phone/ personally identifiable information sufficient for future protections
- Research and Healthcare is built on trust, does the new technology and tool undermine trust?

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ETHICAL ISSUES IN DATA USE AND GOVERNANCE

ADAPTING PAST LESSONS TO EMERGING NEEDS

Carolyn Petersen, MS, MBI, FAMIA

MedInfo 2023
9 July 2023 – Sydney, Australia

OVERVIEW

- Underlying Circumstances
- Privacy Rights
- Concerns to Address

UNDERLYING CONSIDERATIONS

- Push for personalized experiences leading to greater collection of personal data
- Lack of clarity around benefits for citizens/patients
- Potential lack of access to benefits of data sharing
- Complex legal and regulatory environment
- Problems (e.g., bias) and the lack of corresponding solutions becoming visible to public

PRIVACY RIGHTS

- **Information privacy** – the right to control the access to, use of, and dissemination of personal information
- **Communication privacy** – protection from digital eavesdropping and interception
- **Individual privacy** – right to be left alone

CITIZEN/PATIENT CONCERNS TO ADDRESS

- Lack of understanding about what’s being collected
- Lack of awareness about what’s being done with collected information
- Confusion about what choices the law requires they be able to make and what meaningful choices they actually can make
- Lack of understanding about what they can do to limit data collection and sharing
- Use of precise geolocation and other surveillance technology

CITIZEN/PATIENT CONCERNS TO ADDRESS CONT

- Questions about data aggregation and the resulting insights, and how these insights are used with and without consent
- Possibility for personal data to be analyzed for predictive purposes and the accuracy and application of the algorithms used for this analysis
- Use of personal data for purposes unseen or unexplained today
- Monetization of personal information in ways that don’t benefit self and/or society
- Increasing health equity amidst times of technological and social change

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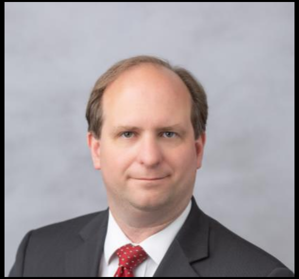
Panel Discussion

Farah Magrabi



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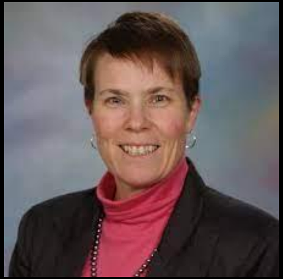

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