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Data Infrastructure, AI, & the Law

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Data & AI

- Training
- Validation
- Oversight
- Re-training

Data Sources (types)

- EHRs/EMRs
- Pharmacy records
- Claims data
- Non-health sources

Data sources (places)

- Academic medical centers
- Insurance companies
- Government? (use restrictions)

Data sources (people)

- Who seeks types of care
- Which care generates data
- Racial/ethnic/SES differences
- Consent/privacy choices

Data fragmentation

- Fragmented health system
 - Different providers
 - Different insurers (med, dental)
- Fragmentation over time
- Interoperability issues

Key legal regimes

- Privacy
- Informed consent
- [interoperability rule]

Privacy

- HIPAA
 - Research \neq permitted use
- State law[s]
- Note: domain-specific!

Informed Consent

- Common Rule
- Medical ethics

De-identification

- HIPAA
- Informed consent
- BUT...aggregation
 - (limits capacity)
 - (data brokers)

Data infrastructure investment

- Rules
- Technical capacity
- Public-good datasets
- Data broker roles (FDA?)

Takehomes

- *Goal:* comprehensive, timely data
- *Challenges:* fragmentation, legal barriers to sharing/use
- *Tension:* privacy/autonomy v public good
- *Potential:* infrastructure investments