# Medical and Genomic Data Privacy

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# Outline

- Medical Data Privacy
- Efforts by Government
  - HIPAA, CMIA, EHR and HITECH
- Medical Data Privacy Protection
  - Technical strategies
- Cross Multiple Institutions
  - CONNECT, the DIRECT Project
  - Privacy preserving medical data mining
- Genomic data security and privacy
  - Unique challenges

# Medical Data Privacy

- Medical data
  - Any information that relates to health or condition of an individual, the provision of health care to an individual, or the payment for the provision of care to an individual.
- Privacy
  - The claim of individuals, groups and institutions to determine for themselves, when, how and to what extent information about them is communicated to others.
- Medical data privacy
  - Individual
  - Institutional

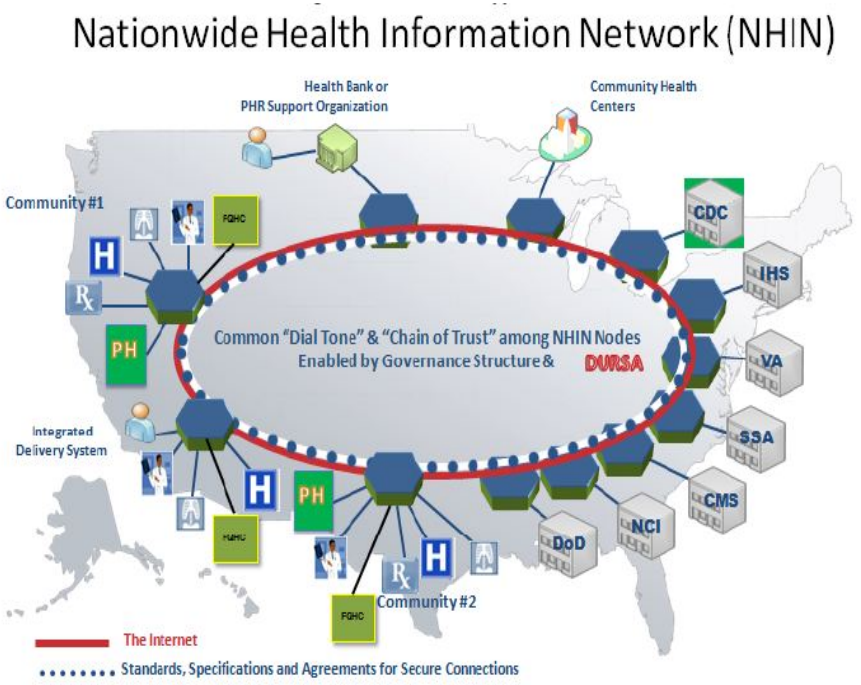
# HIPAA and CMIA

- HIPAA
  - Health Insurance Portability and Accountability Act of 1996 (HIPAA), implemented in 2003.
  - It establishes a federal floor of safeguards to protect the confidentiality of medical information.
  - 18 HIPAA identifiers.
- CMIA in California
  - Confidentiality of Medical Information Act
  - Requires patient authorization for release of information unless release otherwise permitted or required by law

# Government Investment

- U.S. government's investment in Health Information Technology
  - Health Information Technology for Economic and Clinical Health (HITECH) Act of 2009
  - **$29 billion** Electronic Health Records (EHR) reimbursement program
  - Contracts of **$18.6 million** to develop prototypes for the National Health Information Network (NHIN) architecture.

- NHIN
  - Support accurate, timely, appropriate, and secure health-care information exchange.



# Medical Data Privacy Protection

- Data collection
  - Encryption: most vendors use AES. Some accelerations, such as Intel AES-NI.
- Data storage
  - Authentication
  - Access control
  - API security
- Data utility
  - Publishing the de-identified data.

# Medical Data Privacy Protection

- Anonymization before publishing
  - Masking methods: Suppression, generalization, etc.

| Name | Age | Postcode | Sex |
|---|---|---|---|
| Greg | 20 | NW10 | M |
| Jim | 45 | NW15 | M |

External data

| Age | Postcode | Sex | Disease |
|---|---|---|---|
| 20 | NW10 | M | HIV |
| 46 | NW10 | M | Flu |

De-identified data

| Name | Age | Postcode | Sex |
|---|---|---|---|
| Greg | 20 | NW10 | M |
| Jim | 45 | NW10 | M |

External data

| Age | Postcode | Sex | Disease |
|---|---|---|---|
| * | NW10 | M | HIV |
| * | NW10 | M | Flu |

Suppressed data

Example: Value Suppression

# Medical Data Privacy Protection

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External data

| Age | Postcode | Sex |
|---|---|---|
| 20 | NW10 | M |
| 45 | NW15 | M |

De-identified data

| Name | Age | Postcode | Sex |
|---|---|---|---|
| Greg | 20 | NW10 | M |
| Jim | 45 | NW15 | M |

External data

| Age | Postcode | Sex |
|---|---|---|
| [20-45] | NW1* | M |
| [20-45] | NW1* | M |

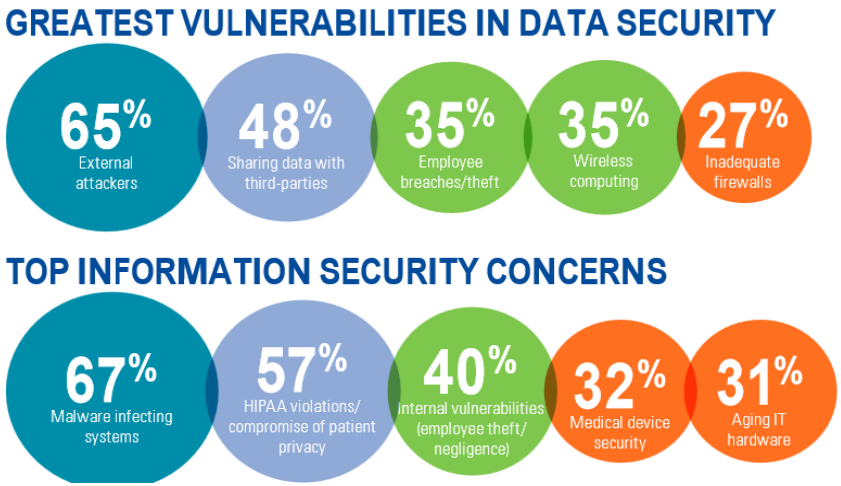
Generalized data

Example: generalization

# Data Across Multiple Institutions

- When personal medical information moves across hospitals, doctors' offices, insurers or third party payers, and state lines.
- The Direct Project (launched 2010)
  - Developing technical standards and services required to enable secure, directed health information exchange among trusted providers.
  - XDR and XDM for direct messaging.
  - SMTP, S/MIME, and X.509 certificates are used.
- CONNECT
  - Free, open source software solution that supports health information exchange
- Nationwide Health Information Network Exchange
  - First community that implements the NHIN standards.
  - Including CDC, DoD, Kaiser Permanente, MedVirginia, etc.

# Data Across Multiple Institutions




Survey by KMPG of 223 healthcare executives in 2015

- Top threats include “Sharing data with third parties”.
- Privacy preserving medical data mining across multiple organizations
  - Collaborative medical research leveraging big data.
  - Both individual and institutional privacy should be protected.
  - Solutions include applications of homomorphic cryptographic algorithms, data transformation, etc.

# Genomic Data Privacy

- Applications of human genome data makes more personalized treatments and preventive healthcare possible.
- Personal genomic data contains highly sensitive information, e.g., prediction of a certain disease.
- Unique challenges in protecting genomic data privacy.
  - Genomic data has a long life span as DNA almost does not change over time. Brute force attackers have more time.
  - Genome itself is the ultimate identifier. Traditional anonymization methods that remove personally identifiable information are not effective.
  - Harder to resolve privacy concerns of genomic data owner to participate in medical research.