Maximizing Value from Government Health Data: A Federal View

Opening Keynote: Big Data Symposium
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Meet Our Speakers

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Conflict of Interest Statement

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Have no real or apparent conflicts of interest to report.
Agenda

- The HHS/CODE Data Sharing Roundtables
- Health Data Privacy
- Social Determinants of Health Data
- Health Data for AI
- Current Challenges and Opportunities
- Q&A
Learning Objectives

• Identify HHS and other health-related datasets of high value, including some of the best ones for specific applications
• List key strategies for balancing privacy protection with health data access
• Explore how social determinants of health data can be used for both public health and individual patient care
• Illustrate how AI applications can improve diagnosis, treatment, and care delivery
Data Roundtables: Collaborating for New Solutions
Three Roundtables in 2019

• Sharing and Utilizing Health Data for AI Applications (April)
• Balancing Privacy with Health Data Access (July)
• Leveraging Data on the Social Determinants of Health (Oct.)

www.OpenDataEnterprise.org/publications
The Patient-Centered Outcomes Research Institute

funds studies that can help patients and those who care for them make better-informed healthcare choices.
The HHS Office of the Chief Technology Officer tests and validates solutions to solve challenging problems in the delivery of health and human services, and promotes innovation across all of HHS.
The Center for Open Data Enterprise (CODE) is a 501(c)(3) non-profit that works to maximize the value of open government data as a public resource, by focusing on data users.
The Opportunity

Data sharing, AI and new data analytics, and SDOH data provide new ways to **improve diagnosis and treatment** by using health data of all kinds - including **clinical data, genomic data, patient-generated data, and social determinants**.
High-Value Health Data

- Administrative and Claims Data
- Clinical Data
  - Clinical Trials Data, EHR Data
- Genomic Data
- Patient-Generated Data
  - IoT Data, Social Media Data
- Social Determinants of Health (SDOH) Data
- Surveillance Data
  - Registry Data, Survey Data, Vitals Data
Health Data Privacy: Federal Context

- Health Insurance Portability and Accountability Act (1996)
- HIPAA Privacy Rule: Defines when and how use and disclosure of PHI is permitted
- HIPAA Security Rule: Focuses on safeguarding electronic PHI
- Enforced by the HHS Office of Civil Rights (OCR), which can administer financial penalties
Other Relevant Regulations

- Privacy Act, 1974: Establishes a code of fair information practices
- Family Educational Rights and Privacy Act (FERPA), 1974: Provides specific guidelines for medical info in student records
- Confidential Information Protection and Statistical Efficiency Act (CIPSEA), 2002: Governs confidentiality for statistical agencies.
- Genetic Information Nondiscrimination Act (GINA). 2008
- State-level laws (Maine, California) for consumer-generated data
Current Legislative Proposals

• Draft Consumer Data Protection Act to expand FTC powers.
• Draft Data Care Act for websites, apps, online providers.
• American Data Dissemination Act – would require Congress to pass laws to strengthen the FTC.
• Protecting Personal Health Data Act – would require HHS to create regulations for health data tracking apps and genetic testing kits.
Current HHS Privacy Reforms

- Proposal to revise 42 CFR Part 2 (relevant to opioid research)
- Request for Information on reforming HIPAA
- Additional measures proposed to make data appropriately usable while protecting privacy
Risks of Ineffective Privacy Protection

• The Mosaic Effect
• Inappropriate Data Sharing and Use
• Confusion About Data Safeguards and Protection
• Specific Risks:
  • Genomic data
  • Consumer-generated data
  • SDOH data
Benefits of Appropriate Data Sharing

- **Patients**: Awareness of health risks, increased knowledge and empowerment, better research
- **Communities**: Addressing health disparities, improving and targeting social services, increasing federal grant money
- **Providers**: Coordinated care, reduction of costs, increased revenue, better understanding of patients’ needs and options
- **Federal government**: Enhanced research, improved ability to serve Medicare and Medicaid beneficiaries, reducing costs
- **Public health agencies**: Control of disease outbreaks, improved administration of services
Example: Establishing Privacy Principles for Precision Medicine
SDOH: The federal and public-private context

- Healthy People 2020
- National Library of Medicine: Open source FHIR-enabled questionnaire
- The Gravity Project
- Social Determinants Accelerator Act (proposed)
- NACHC: PRAPARE Assessment Tool
## Figure 1

### Social Determinants of Health

<table>
<thead>
<tr>
<th>Economic Stability</th>
<th>Neighborhood and Physical Environment</th>
<th>Education</th>
<th>Food</th>
<th>Community and Social Context</th>
<th>Health Care System</th>
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<td>Housing</td>
<td>Literacy</td>
<td>Hunger</td>
<td>Social integration</td>
<td>Health coverage</td>
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<td>Income</td>
<td>Transportation</td>
<td>Language</td>
<td>Access to healthy options</td>
<td>Support systems</td>
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<td>Safety</td>
<td>Early childhood education</td>
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<td>Community engagement</td>
<td>Provider availability</td>
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### Health Outcomes

Mortality, Morbidity, Life Expectancy, Health Care Expenditures, Health Status, Functional Limitations
Potential for SDOH Application

• The drug overdose crisis
• Infant mortality
• The obesity epidemic
• Dementia
• HIV/AIDS
Potential for an HHS SDOH Data Strategy

• Define and standardize SDOH data
• Create a sustainable SDOH data infrastructure
• Support local and state-based decision-makers
• Improve and align open source assessment tools
• Adopt data standards and definitions
• Strengthen data-gathering by providers and CBOs
• Support both state-level and hyperlocal data gathering efforts
Example: Precision Medicine with SDOH Data
AI: The federal context

- HHS AI Strategy – under way
- National AI R&D Strategic Plan (June 2019)
- Launch of National AI Institute (NAII) at VA
- Executive Order on Maintaining American Leadership in AI (February 2019)
Executive Order on American Leadership in AI

- Investment in AI R&D
- Enhance access to federal data, models, and computing resources
- Reduce barriers to use of AI
- International standards to minimize vulnerability
- Train American AI researchers and users
- Develop and implement an action plan
Benefits of AI for Health

• **Reducing costs and administrative burden.** E.g., NLP to process EHRs.

• **Connecting patients to resources and care.** E.g., sensors and mobile tech to monitor and coach patients.

• **Informing population health management.** E.g., combining SDOH and clinical data to predict and prevent opioid abuse.

• **Improving diagnosis and early detection through “augmented intelligence.”** E.g., using image recognition, NLP, and deep learning to diagnose diabetic retinopathy, brain injury, other illnesses.

• **Developing new drugs and therapeutics.** E.g., enhancing drug discovery, analyzing biomarkers, matching patients to clinical trials.
Example: The HHS AI Health Tech Sprint
Current Challenges and Opportunities

• Public-Private Data Exchange
• Privacy and Security
• Social Determinants of Health
• AI: Challenges and Opportunities
• The Patient’s Role
Public-Private Data Exchange

• How do we identify the best opportunities for public-private data sharing in health?

• How can we manage business risks in sharing proprietary data?

• What are the potential benefits to:
  • Business
  • Government
  • Patients
Privacy and Security

• How well is HIPAA working to achieve the balance of privacy protection and appropriate data use?

• Do we need:
  • Changes to HIPAA
  • New legislation
  • Better education about HIPAA
  • All of the above?
Privacy and Security

• What technical approaches – de-identification, anonymization, differential privacy, synthetic data, and so on – show the most promise for using health data in research?

• What are the acceptable tradeoffs in using them?

• What should be the role of data enclaves, and how should access to them be managed for public-sector, private-sector, and academic stakeholders?
Social Determinants of Health

• How can healthcare providers and plans use SDOH data to improve:
  • Assessments for value-based care
  • Individual patient care
  • Community outreach
Social Determinants of Health

• What are the best sources of SDOH data at a community and individual level and how should each be used? Including:
  • Community data – from city-level to census tract level
  • Individual data from questionnaires
  • Individual data from patient records
  • Other sources
AI: Challenges and Opportunities

• How can AI help improve care for individual patients? Including the use of:
  • EHRs
  • Claims data
  • SDOH data
  • Other data
AI: Challenges and Opportunities

• How can AI reduce cost and improve the effectiveness of care? Including:
  • Identifying at-risk groups and individuals
  • Assessing value of care
  • Reducing waste, fraud, and abuse
AI: Challenges and Opportunities

• How can we reduce the risk of negative consequences from AI? Including:
  • Algorithmic bias
  • Negative consequences of identifying at-risk individuals or populations
The Patient’s Role

• How can we bring patients into the conversation about health data? How can we address appropriate concerns about:
  • Privacy of their data
  • Analysis of their data
  • Sharing of their data
The Patient’s Role

• Can we encourage patients to volunteer their data for research purposes? What are the implications for:
  • HIPAA
  • Informed consent
  • Data management
Q&A
Thank you

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