Divergence and Convergence in APCDs: A Multi-level Study of the APCD Movement in the U.S.

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Our research project

• How do new organizational forms of health data governance emerge, gain legitimacy, and evolve?
  • APCDs as an exemplar (history, multi-state, well documented)
  • Longitudinal, cross-sectional (National), in-depth case studies

• Study methods
  • Interviews (45 to date)
  • Participation in NAHDO (2018-2020)
  • Document review (NAHDO, APCD Council, state APCD websites, legislation, whitepapers, academic articles, etc.)

• Finishing with data collection, analysis, and beginning reporting and feedback this fall.
Research insights on emergence of APCDs in US: Variability

What explains the variability in this map?

- “When you’ve seen one APCD you’ve seen one APCD.”
- Why were some states first to adopt?
- Why have some states not moved forward with an APCD?
- Why do some states remain voluntary?
- Why is there diversity in APCDs structure?

Our analysis as of Spring, 2020.
For comparison, also see: https://www.apcdcouncil.org/state/map
Research insights on emergence of APCDs in US: Structural Variation

- **Position in state governance**
  - Division of state agency, state agency (usually DOH), designated NfP, independent NfP

- **Governance structure**
  - Policy committee with key stakeholders
  - Data request/authorization committee
  - Separation of data stewardship and analytics

- **Data types included in APCD**
  - Hospital discharge (y/n)

- **Data operations (collection & warehousing)**
  - Outsourced (most) vs inhouse

- **Data release policies**
  - Who can access or request data (very limited to very broad)
  - E.g., State agencies, researchers, commercial firms, public

- **Funding sources**
  - State budget vs set-aside funds/tax; Medicaid admin share
  - Grants
  - Data sales
Research insights on emergence of APCDs in US: External Influences

Increasing Healthcare costs, market complexity, state regulatory oversight

Community Initiatives

Regulatory change

Grant & other funding

Economic change

Other external forces

 ACA passed

Rate regulation, transparency

Recession

5th APCD/NAHDO conference

Regional APCD council & conference

AHRQ grants

CCIO Cycle III

Insurance industry pushback

APCD data submission standards

AI/ Machine learning

Medicaid & SIM-Related Funds

COVID-19 Pandemic & Recession

COVID-19 data analysis

2003 Maine

2004 South Carolina (voluntary)

2005 Vermont Wisconsin (voluntary)

2006 Maryland New Hampshire

2007 Michigan (voluntary)

2008 Kansas Minnesota Rhode Island

2009 Oregon Oklahoma (voluntary)

2010 Colorado Tennessee (inactive)

2011 New York West Virginia (inactive) Virginia (no mandate)

2012 Connecticut Massachusetts

2014 Gobeille v. Liberty Mutual filed

2015 Arkansas

2016 Gobeille decision Florida Hawai’i Texas (voluntary) Utah

2017 Delaware Washington

2018 California Virginia (mandated)

2020 New Mexico (inactive) Georgia

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Research insights on emergence of APCDs in US: Emergence of Use Cases

- **Managing and regulating health care markets**
  - Cost and spending trends
  - Prescription and drug spending
- **Insurance access and coverage**
  - Enrollment
  - Geographic differences
  - Insurance coverage
  - Service utilization
- **Price transparency**
- **Quality-related topics**
  - Population health
  - Quality improvement
- **Impacts of public health emergencies**
  - Opioid epidemic drivers
  - COVID-19 impact (health spending, costs)

**Challenges**
- Limits of claims data & need to link data
- Timeliness of feeds and access to data
Research insights on challenges and opportunities with APCDs

• **Challenges**
  
  • Sustainability: budgets, cost increases, priorities
  • Payment reform and shift from claims data to APM data
  • Efforts to arrive at MOU / DUA for cross-department data analysis
  • Tensions in standardization (between states, states vs national)

• **Opportunities**
  
  • Techniques for privacy-preserving linkages (hashing) for novel uses cases with multiple data sources
  • Advances in technologies (AI, machine learning)
  • Increasing demands for evidence-based policy making and evaluation
We would like your feedback and insights!

• Suggestions for improving and extending analysis
• Opportunities and challenges for APCDs you see, areas of change

We plan to share our findings via technical reports to the community, after they have been vetted.

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