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

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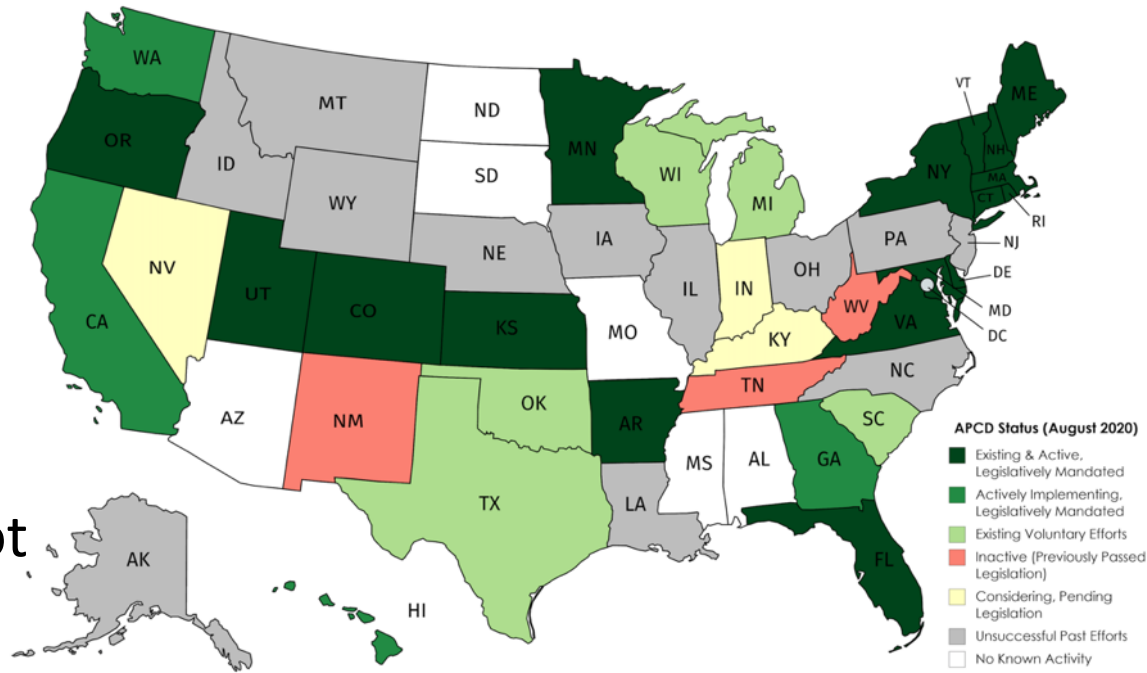Myron B. Thompson School of Social Work
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Our research project

- *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?

APCD Status (August 2020)
- Existing & Active, Legislatively Mandated
- Actively Implementing, Legislatively Mandated
- Existing Voluntary Efforts
- Inactive (Previously Passed Legislation)
- Considering, Pending Legislation
- Unsuccessful Past Efforts
- No Known Activity

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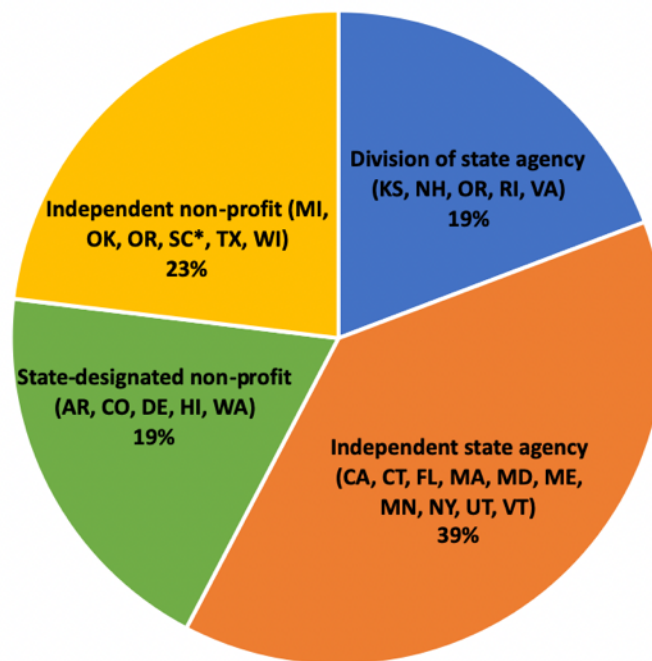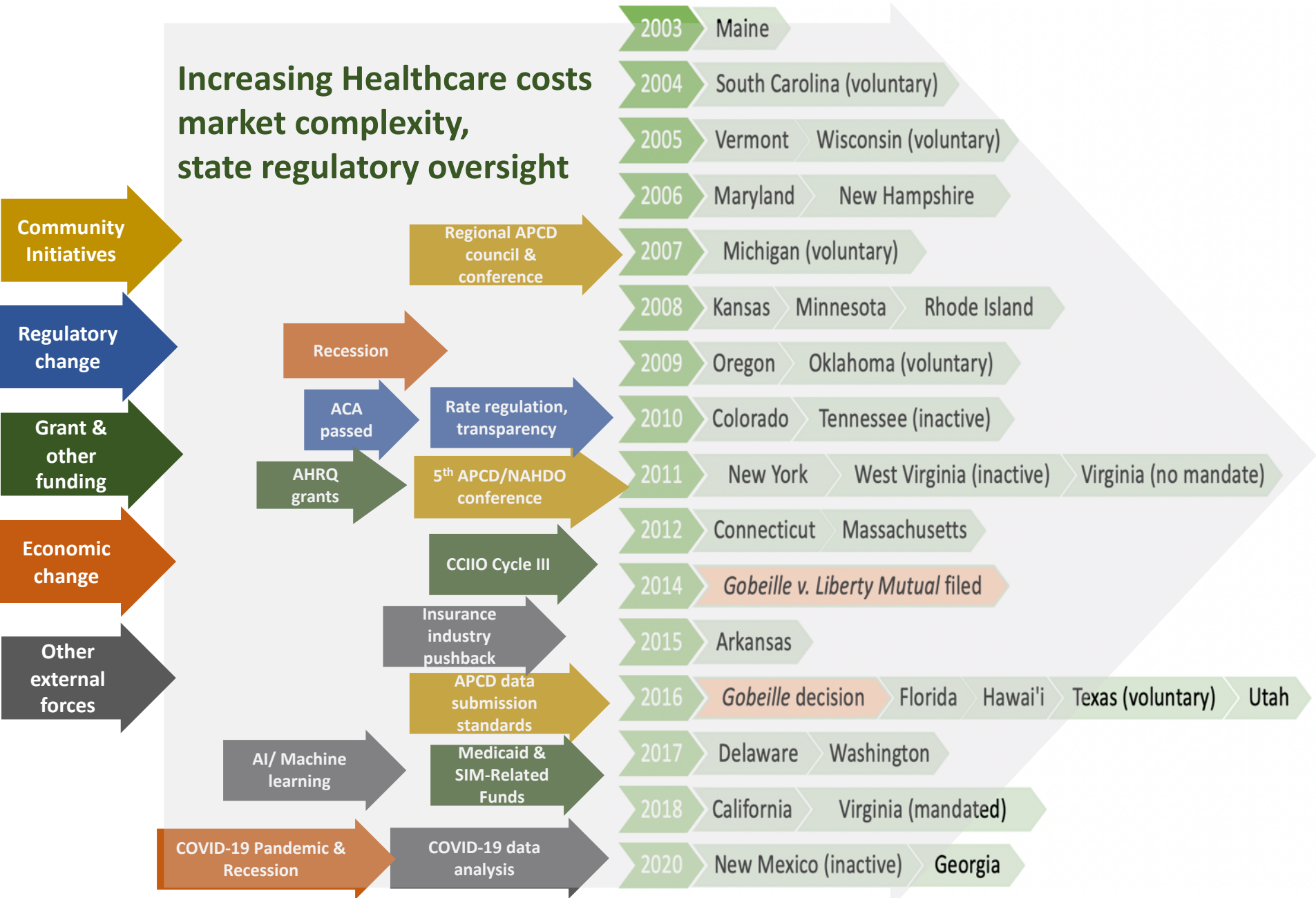
Research insights on emergence of APCDs in US: Structural Variation

- **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

APCD Organizational Form
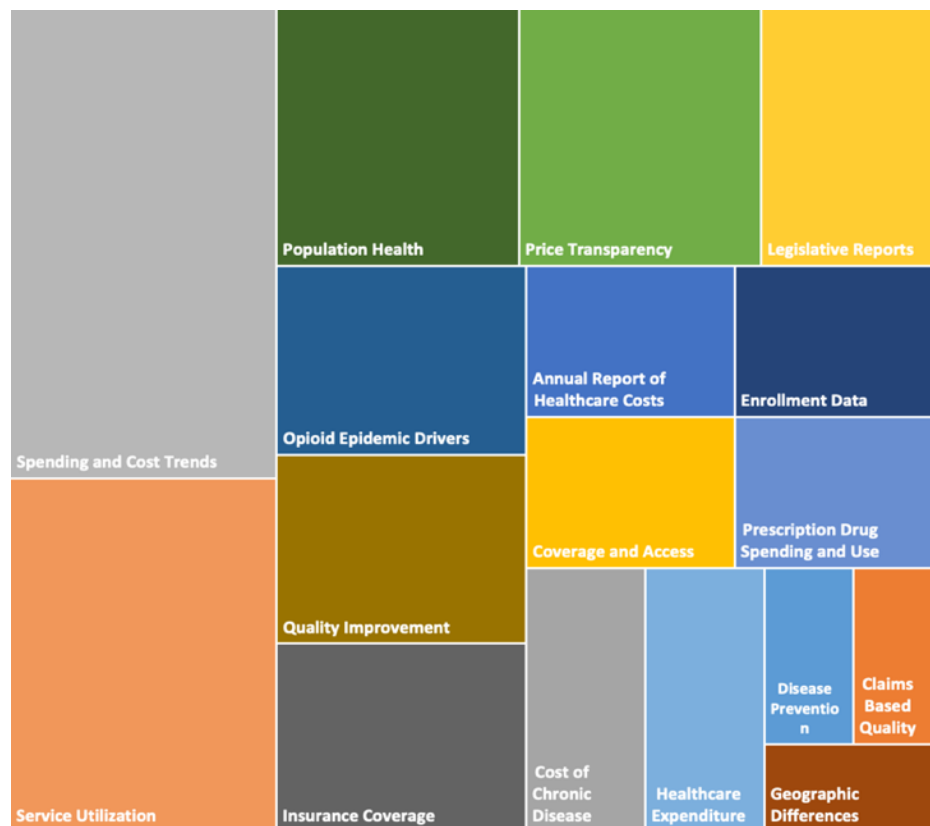
- Division of state agency (KS, NH, OR, RI, VA) 19%
- Independent state agency (CA, CT, FL, MA, MD, ME, MN, NY, UT, VT) 39%
- State-designated non-profit (AR, CO, DE, HI, WA) 19%
- Independent non-profit (MI, OK, OR, SC*, TX, WI) 23%

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

Regional APCD council & conference
Recession
ACA passed
Rate regulation, transparency
AHRQ grants
5th APCD/NAHDO conference
CCIIO Cycle III
Insurance industry pushback
APCD data submission standards
AI/ Machine learning
Medicaid & SIM-Related Funds
COVID-19 Pandemic & Recession
COVID-19 data analysis

Year				
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		

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.

Please feel free to contact us at:

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