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NEHI is a national health policy institute focused on enabling innovation to improve health care quality and lower health care costs.

In partnership with members from all across the health care system, NEHI conducts evidence-based research and stimulates policy change to improve the quality and the value of health care.

Together with this unparalleled network of committed health care leaders, NEHI brings an objective, collaborative and fresh voice to health policy.

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**INTRODUCTION**

All Payer Claims Databases (APCDs) have grown in popularity over the last few years, with more than 30 states now having an APCD in place, in process, or expressing strong interest in developing a system.<sup>1</sup> APCDs regularly collect medical claims and pharmacy claims data, with some also collecting dental claims and eligibility data, from both private and public payers. While claims data analysis is not new, these comprehensive, longitudinal, multi-payer datasets are now providing unprecedented research and policy opportunities for improving the health care delivery system.

Nevertheless, the APCD landscape is still very much in its infancy and the potential of these systems is in many ways underutilized. State policymakers are grappling with several issues, including: how best to define the use cases of the system, demonstrate the value of the system, and whether to open access to external researchers. On November 4, 2014, NEHI convened national experts including state leaders and academic and commercial researchers to explore the opportunities and lessons learned in leveraging APCDs to advance health services research. (Please see Appendix for a list of speakers.)

Key findings include:

*Use Cases are Evolving Over Time:*

As of March 2014, 11 states had an APCD in place and five states were in process of implementation. Of those states, nine were issuing reports based on their APCD data, and use cases varied considerably.<sup>2</sup> To date, APCDs have been primarily designed to address the interests of stakeholders engaged by developers: for creating price transparency, monitoring state-level payment reform and delivery reform initiatives, and promoting population health efforts.<sup>3</sup> While some APCD administrators are developing strong use cases for their APCD systems, other states are finding difficulties due to limited resources, lack of stakeholder buy-in, and privacy concerns. Well-established APCDs have devoted more time and energy toward developing broad design goals, and expanding stakeholders and users early on. Experts agreed that at a minimum, use cases need to be defined very specifically and through a clear planning process.

*Use Cases Must be Clear and Demonstrate Value to a Broad Set of Stakeholders:*

Experts agreed that for APCDs to be politically and financially sustainable, states need to design APCD systems based on a common vision of use, and be able to prove value to policymakers and end-users early on. APCD administrators should articulate goals as early as they can and should develop a process for building consensus around a shared vision and a plan for bringing it there.

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States are following different strategies to prove the value of their system and to make it worthwhile to stakeholders. For example, Massachusetts is partnering with state agencies to generate good will and a broader network of support for the APCD within the state, identifying ways the APCD can promote administrative simplification for stakeholders in such areas as commercial insurance rate review and insurance exchange operations. Possible future work includes a partnership with the Department of Public Health and linking the APCD system to its vital records and cancer registry, along with the development of integrated datasets for clinicians.

Colorado intends to offer subscriptions for continually updated, standardized datasets and analytic tools to particular stakeholders. The administering organization, Center for Improving Value in Health Care (CIVHC), also hopes to build partnerships with commercial entities, such as digital health innovators and technology developers, creating new opportunities to push the data out to the health care community, while developing strong privacy safeguards.

On the other hand, Minnesota is an example of an APCD with a statutorily explicit use case, and as a result has had considerable difficulty evolving to meet the needs of stakeholders. Experts broadly agreed that the greatest value will be in providing data that is actionable, regardless of the approach.

#### *Broad Data Access is Important, With Appropriate Checks and Balances*

In addition to reports and analysis, six states currently are releasing data externally: Colorado, Massachusetts, Maine, New Hampshire, Oregon, and Vermont.<sup>4</sup> States with data release policies must define principles for research that meets the public interest, and then assess requests in line with those standards. For many states this is a delicate subject, especially as policymakers consider releasing datasets to commercial entities and releasing datasets that potentially pose the risk of re-identification.

Despite privacy and security concerns, experts agree that APCD data is an important resource and should be viewed as a public good available to a variety of users, including commercial interests, with appropriate check and balances. For example, commercial entities may have alternate skill sets from APCD administrators that can be leveraged to use the data in new and innovative ways. Not only is this an opportunity to create a shared learning community, it is also a way for states to improve processes and find data errors and system errors more quickly.

#### *Price Transparency Should Not be the Primary Goal*

APCD systems can lend themselves to broad health care price transparency initiatives, helping inform policies that create a more competitive health care marketplace. Colorado, for example, is leading the cost-transparency charge by piloting a transparency website platform for the public.

However, experts agreed that while price transparency initiatives are valuable, they are not necessarily a sustainable model for ongoing engagement with stakeholders and consumers. Consumer facing web site development and maintenance is generally considered not to be core skills of state agencies. There are also other important price transparency initiatives taking place in the private sector. For example, commercial entities – such as payers and technology developers – may be better suited to use the APCD databases and create their own consumer centric platforms that promote transparency given their established connection to their members and technical capabilities. Experts agreed that it was unlikely for APCDs to become the go-to resource for consumer price/cost transparency information.

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### Voluntary and Private Models Can Play an Important Role

State-led APCDs are part of an expanding health care data landscape that consists of a range of voluntary, private, regional and national claims-database collaborations across the country – including efforts made by the Network for Regional Healthcare Improvement (NRHI) and the Health Care Cost Institute (HCCI). Experts agreed that with coordination and collaboration these diverse initiatives can be complementary to one another and do not need to compete with state-led APCDs. Experts agreed there is room for many players, and quarrels over data ownership are not productive.

### **UNLOCKING THE POTENTIAL**

It is clear that the APCD landscape has a great deal of potential that is slowly being realized, already proving value in its early years by informing policies that create a more competitive health care environment and improve patient care. APCDs are a vital tool for understanding cost and utilization across populations and over time. The broader potential of APCDs deserves thoughtful attention from the health care and health policy communities and, according to the experts at the NEHI convening, includes the following issues:

#### Moving Beyond Claims Data

The next step for APCDs will be to integrate other non-claims data sources, such as patient registries, vital records, clinical data, and patient reported surveys. The challenges to such efforts are substantial, and include interoperability barriers, maintenance of secure systems across all data warehouses, currently lacking clinical data sets, and difficulties matching clinical and claims events.<sup>5</sup> Nevertheless, this is a real vision for APCDs and several states are already looking into what it will take.

#### Releasing Identified Data is Valuable

Experts agreed that APCDs should consider the value of identified datasets for limited purposes, given that appropriate protections are in place. Providers may leverage identified datasets to detect outliers in patient care and incorporate patient histories and care rendered outside their site of care into practice management. Payers would be able to leverage more robust patient histories and manage patient care earlier following plan enrollment. Additionally, researchers would be able to leverage multi-carrier, de-identified datasets to address questions related to long-term outcomes and impact of benefit designs on outcomes. This will be extremely important for the future, and there are technologies available now that can provide appropriate protections.

#### Exploring New Partnership Opportunities

Currently, the majority of APCD use cases are by state agencies, and broader research requests are coming from the academic community – but this might change in the future. States are beginning to actively engage with new stakeholders in academic and commercial communities on new data uses and analysis. Experts agreed that broader data access, with appropriate checks and balances and established analytic standards, would be beneficial and leverage more fully the capability of the data and provide a path for sustainability as APCDs evolve and incorporate richer features.

While the focus of APCD efforts to date has been on applications within state government policy and administrative functions and some health services research, there is enormous opportunity for other health sectors to become involved in these initiatives and to take APCD system capabilities further. This will require all sectors being at the table – state agencies, payers, providers, patients, and industry – to discuss how to best unlock the potential of these efforts.

## APPENDIX

### All Payer Claims Databases: Unlocking the Potential

November 4, 2014

Renaissance Boston Waterfront Hotel, Boston, Massachusetts

#### Expert Panel:

**Áron Boros**, Executive Director, Center for Health Information and Analysis (CHIA)

**Ana English**, CEO, Center for Improving Value in Health Care (CIVHC)

**John Freedman, MD**, Principal, Freedman HealthCare

**Stefan Gildemeister**, Director, Health Economic Programs, Minnesota Department of Health

**Jonathan Gruber, PhD**, Ford Professor of Economics, MIT Department of Economics

**Marilyn Schlein Kramer**, Deputy Executive Director for health information, Center for Health Information and Analysis (CHIA)

**Elizabeth Mitchell**, President and CEO, Network for Regional Healthcare Improvements (NRHI)

**Kenneth Park, MD**, Vice President, Payer and Provider Solutions, HealthCore

**Josephine Porter**, Deputy Director, Institute of Health Policy & Practice, University of New Hampshire

**Jennifer Ricards**, Senior Research Fellow, State Health Access Data Assistance Center (SHADAC), University of Minnesota

**Moderator: Tom Hubbard**, Vice President of Policy Research, NEHI

**Moderator: Christopher Koller**, President, The Milbank Memorial Fund

## ENDNOTES

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<sup>1</sup> Porter, J., Love, D., Peters, A., Sachs, J., & Costello, A. (2014 January). The basics of All-Payer Claims Databases: A primer for states. [http://www.rwjf.org/content/dam/farm/reports/issue\\_briefs/2014/rwjf409988](http://www.rwjf.org/content/dam/farm/reports/issue_briefs/2014/rwjf409988)

<sup>2</sup> Porter, J., & Green, L. (2014 March 25). All Payer Claims Databases: Current status and realizing the potential. State Health and Values Strategy Program, Robert Wood Johnson Foundation [presentation].

<http://apcdouncil.org/sites/apcdouncil.org/files/2014-03-25%20RWJ%20Realizing%20APCD%20Potential.pdf>

<sup>3</sup> State Health Access Data Assistance Center (SHADAC). Making use of All-Payer Claims Databases for health care reform evaluation [draft white paper]. <http://www.shadac.org/publications/making-use-all-payer-claims-databases-health-care-reform-evaluation>

<sup>4</sup> APCD Council. Data requests. (July 2014). <http://apcdouncil.org/data-requests>

<sup>5</sup> HealthInfoNet. (2013 June 5). Matching Maine's HIE clinical and APCD claims data: Report on proof of concept to match HealthInfoNet identified HIE clinical data to de-identified commercial claims data from the Maine Health Data Organization.

[https://mhd0.maine.gov/\\_pdf/MHDO\\_HIN%20Claims%20Matching%20Report%206%204%2013.pdf](https://mhd0.maine.gov/_pdf/MHDO_HIN%20Claims%20Matching%20Report%206%204%2013.pdf)