NAHDO
ANNUAL REPORT
Fiscal Year 2019

November 2019

THE NATIONAL ASSOCIATION
OF HEALTH DATA ORGANIZATIONS

Mission Statement

The Organization is charged with the charitable and educational purposes of assisting state health data organizations and members of the public by creating, exchanging, and providing information and resources that promote the effective collection, analysis, and dissemination of health care data.

The Organization aims to meet its purpose by developing and facilitating networks of health information professionals to:

- Advocate for proper protections of health information while preserving access to such data by the appropriate users

- Promote comparability of health information through the development of guidelines and standards for data collection, analysis, and dissemination

- Share and transfer knowledge across a diverse network of individuals and organizations

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About NAHDO...

NAHDO is a non-profit 501-C-3 membership and educational organization, established in 1987, to promote the public availability of health care data and improve statewide health care surveillance systems.

To achieve its mission, NAHDO provides technical assistance and guidance to states and advocates for uniformity in data standards. NAHDO is governed by a Board of Directors whose members are from public and private organizations and recognized nationally for their expertise in the health information industry.

NAHDO convenes experts in national meetings, testifies to national and state policymakers, and implements grants and projects consistent with its mission. Through membership, meetings, and projects (such as the Healthcare Cost and Utilization Project (HCUP), NAHDO-CDC Cooperative Agreement, and AHRQ's Building Research Infrastructure and Capacity Program), NAHDO has established working relationships with health information professionals in all 50 states, including private sector and local health agencies in many of these states.

NAHDO's members are experts in health care data collection and use and represent the only community of practice dedicated to population-based health care data issues.

Letter from the Executive Director

As NAHDO enters its 34th year, I take this opportunity to reflect on our mission, our accomplishments, and look ahead to tremendous opportunities and challenges that lay ahead. And, because I have been a part of NAHDO for 25 of these 34 years, first as a Board member and as its Executive Director these past 20 years, I feel compelled to share a little history and context to this thing called NAHDO.

There are a number of NAHDO pioneers not present, but many of their successors are. In 1986, leaders from Massachusetts, Arizona, Illinois, Iowa, Florida, New Jersey, Colorado, New Hampshire, and Tennessee were among the first executive board members of NAHDO, taking a big risk at that point. Public data was not a popular activity and these leaders were not popular with the industry. Willis Goldbeck, Founder of the Washington Business Group on Health and NAHDO, has shared how these folks were roundly attacked in their own states and in Congress, for having the temerity to suggest that there ought to be any cross-state coordination of data. But they—-and all of us here today—-persisted.

2020 is around the corner and it's remarkable that NAHDO's mission is as relevant as it was 34 years ago. State health data portfolios are exploding way beyond hospital discharge data to include All-Payer Claims Databases (APCDs). APCDs are steadily expanding and supporting the pressing issues of price transparency, delivery system performance, and challenging how we define value in health care. Investing in and defending these awesome data systems is up to today's leaders which will face their own push-back and challenges.

All of us should stay focused on why we do this (sometimes thankless) work and why we must persist, I share Willis Goldbeck's words to our members at NAHDO's 30th Annual Meeting:

> *The greatest challenge we face is neither technical, political, economic nor medical, but rather to remember that we are here to improve human life, to reduce suffering, to facilitate responsible allocation of our public and private resources, to serve and to further the cause of consumers. And that cause is to improve their health, their total health. That's what I started the meeting with in '86 and I wouldn't change a word of it today*

It is with mixed feelings that I write this, my last letter as NAHDO's Executive Director. The past 20 years have been amazing. I've had the privilege of representing state health data agencies on numerous panels, including the National Academies/National Research Council's Panel on Eliminating Health Disparities: Measurement and Data Needs. I've been a "health data missionary" traveling to India and to almost every state and I've mid-wifed more than a few state data systems. I admire the grit and hard work of NAHDO's members and have forged strong bonds with an amazing health data community.

But it is time for new leadership to take on tomorrow's challenges, bring new energy and ideas to the complex field of state health data and health data policy. I welcome Norman K. Thurston, Ph.D. as NAHDO's new Executive Director.

I call for NAHDO's members and stakeholders to work diligently together to shape a bright new future for health care data. We've seen tremendous technical and data system changes—-but some things have **not** changed over the last 34 years. **Leadership matters!**

Sincerely,

PROJECTS AND COLLABORATIONS FY 2019

NAHDO relies on grants and contracts as its major source of revenue. NAHDO's grants and contracts help support our mission and the products and services generated through the grants benefit our members. During FY 2019, NAHDO continued its collaborations with our federal partners:

- The Centers for Disease Control and Prevention's (CDC) Environmental Public Health Tracking Network (EPHTN) NAHDO-CDC Cooperative Agreement (Year 2 of 5), *Identifying Common and Unique Barriers to the Exchange of Hospital Inpatient and Emergency Department Data,* building on its past Tracking accomplishments and relationships to:1) maintain and improve access to statewide health outcomes data; 2) strengthen data steward and Tracking grantee data partnerships; and 3) work with Tracking grantees and CDC staff to enhance the utility of statewide health care data; 4) advance workforce capacity in the use of hospitalization data; and 5) increase awareness of Tracking as a key partner to NAHDO's stakeholders.

- The Agency for Healthcare Research and Quality (AHRQ) Three-year Small Conference Grant, *"Improving the Utility and Comparability of Health Care Data for Health Services Research, Policy Decisions and Transparency Reports",* in the AHRQ category of "Dissemination and Implementation" to improve the utility and comparability of statewide hospital and claims-based data sets for health services research, policy decisions, transparency, and other broad uses. The funding request will provide a unique opportunity to leverage NAHDO conferences, its convening expertise, and sustain adjunct activities throughout the year, beyond an annual conference, to support multi-state shared solutions.

EPHTN Project, Year 1 Highlights:

- Developed, tested, and conducted an online Needs Assessment Survey for state Tracking recipients and received OMB approval

- Participate in Content Workgroups and Sub-county workgroups

- Preparations to update the NAHDO data agency inventory

AHRQ Project, Year 1:

- Conducted a Data Quality Workshop to identify priorities and actions

- Wrote a white paper based on the workshop and post-workshop activities

- Coordinated the Data Quality Forum's development and testing of data quality benchmark metrics

- Planned Year 2 Workshop agendas for Data Acquisition and Enhancement

Other Federal Subcontracts/Projects:

- Subcontractor to IBM-Watson for AHRQ's Healthcare Cost and Utilization Project: Partner Technical Support and National Standards Representation (NUBC/NUCC).

Other Projects FY 2019

California HealthCare Foundation

- The ABCs of APCDs: How Have States Used Data to Understand Cost Drivers, Behavioral Health Needs, and Population Health
- Consultation and Advisory Services to OSHPD's Cost Transparency Healthcare Payments Program

Idaho Department of Insurance

- Addressing Out-of-Network and Balance Billing Issues: A Review of State and Federal Activity and Recommendations for Idaho

California Office of Statewide Health Planning and Development

- California Healthcare Cost Transparency Database Technical and Subject Matter Expertise

NAHDO Projects

NAHDO Data Quality Forum

The Data Quality Workshop recommended several priorities for NAHDO and state action in FY 2019: A Data Quality Benchmarking Project (see results on page 6) and finalization of the APCD-CDL™ (see page 7).

Data Quality Forum Benchmarking Pilot

- Identify key cross-state metrics to compare data quality benchmarks
- Develop metrics that are proxy measures of data quality and are easily generated by state data agencies
- Test the feasibility of calculation and sharing of metrics across states for submission to NAHDO
- Data call issued June 25, 2019 for CY 2017 APCD and Hospital Discharge Data Sets

Preliminary Findings

Less variation in inpatient data sets, and higher race/ethnicity capture in inpatient data

Discover what state APCDs with high valid NPI and commercial percentages are doing and share best practices

Next Steps:

Expand state participation
Refine metrics

Source of Payment Typology: Coordination and Maintenance

NAHDO assumed coordination of this typology, making it available to users **version 9**. The **Source of Payment Typology** is a standardized Payer Type classification system. It is a mechanism for consistent reporting of payer data to state health data organizations and supports data comparisons by payer type across states, various provider types, and to national benchmarks. Developed by the Public Health Data Standards Consortium (PHDSC) Payer Typology Subcommittee, the typology includes broad hierarchial payer type categories with more specific subcategories.

OTHER PROJECTS FY 2019

APCD Measures: 2017 claims
States reporting: 5

Measures	High	Low	Average
% records with valid NPI	100%	92.7%	97.32%
% claims with valid secondary Dx (2,3,4 etc)	78%	53%	63%
% OP facility w valid CPT	99.24%	78.02%	91.9%
% members w valid race	44%	13.1%	28.4%
%members w valid ethnicity	34.72	0	11.5%
% comm <65 w Rx/Med eligibility	96%	45%	76.5%
% comm market represented	81%	34.9%	56.1%
% claims = 0/commercial	58.8%	40.4%	48%
Most recent month	April 2019 commercial	Medicare FFS 2017	

Inpatient Discharges, CY 2017
States reporting: 7

Measures	High	Low	Average
% w secondary diagnosis	99.9%	98.5%	98.8%
% valid race code	99%	80.5%	91.2%
% valid ethnicity	98.6%	32.5%	65.4% (of states collecting)
% MSDRG ungroupable	1.25%	0	.2%
% Medicare as payer	45.9%	27.1%	37.5%
%HMO/MCO as payer	11.3%	.35%	N/A
% Duals	7.73%	.9%	N/A
% Medicaid as payer	26.45%	15.5%	23.9%
% MCO as payer	15.22%	.86%	N/A
% commercial payer code	47.2%	7.79%	29.1%
% Self/charity pay	6.57%	1.5%	3.27%
% Other pay	4.62%	0	3.9%

APCD Council

The APCD Council is a learning collaborative of government, private, non-profit, and academic organizations focused on improving the development and deployment of state-based all payer claims databases (APCDs).

The APCD Council is convened and coordinated by the Institute for Health Policy and Practice (IHPP) at the University of New Hampshire (UNH) and the National Association of Health Data Organizations (NAHDO).

Our goals and activities as a learning collaborative are to:

- Share learning amongst APCD stakeholders, including webinars supported by sponsors
- Provide early stage technical assistance to states
- Catalyze states to achieve mutual goals.
- Bi-monthly state calls and quarterly Learning Network calls

FY 2019 Accomplishments

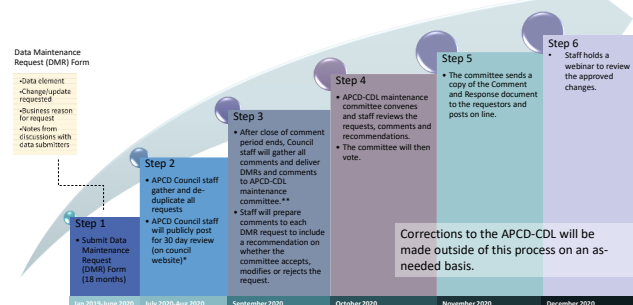- Response to CMS CY 2020 Medicare Hospital Outpatient Prospective Payment System (OPPS) and Ambulatory Surgical Center (ASC) Payment System Proposed Rule
- APCD Council Comments to Confidentiality of SUD Patient Records SAMHSA NPRM
- Response to the Lower Health Care Costs Act
- Response to Protecting Patients from Surprise Medical Bills Act
- Senate Request about Transparency

APCD-CDL™

The purpose of the Common Data Layout (CDL) for All-Payer Claims Databases (APCD-CDL™) is to harmonize the claims collection effort across states and reduce the burden of data submission. The overall goals of this effort are to improve efficiency, reduce administrative costs and improve accuracy in claims data collection

APCD-CDL™ is provided to the non-profit community by NAHDO and The University of New Hampshire for non-commercial purposes only. For-profit or commercial uses of APCD-CDL™ must receive written approval from the Institute of Health Policy and Practice at the University of New Hampshire at its sole discretion, and may require a license

APCD-CDL™ Maintenance Process

Data Maintenance Request (DMR) Form
- Data element
- Change/update requested
- Business reason for request
- Notes from discussions with data submitters

Step 1
- Submit Data Maintenance Request (DMR) Form (18 months)

Jan 2019-June 2020

Step 2
- APCD Council staff gather and de-duplicate all requests
- APCD Council staff will publicly post for 30 day review (on council website)*

July 2020-Aug 2020

Step 3
- After close of comment period ends, Council staff will gather all comments and deliver DMRs and comments to APCD-CDL maintenance committee.**
- Staff will prepare comments to each DMR request to include a recommendation on whether the committee accepts, modifies or rejects the request.

September 2020

Step 4
- APCD-CDL maintenance committee convenes and staff reviews the requests, comments and recommendations.
- The committee will then vote.

October 2020

Step 5
- The committee sends a copy of the Comment and Response document to the requestors and posts on line.

November 2020

Step 6
- Staff holds a webinar to review the approved changes.

December 2020

Corrections to the APCD-CDL will be made outside of this process on an as-needed basis.

*Reflecting APCD-CDL™ development process. ALL states, payers, vendors, and data users may submit comments.
**Council staff and state members of NAHDO

FINANCIAL REPORT FY 2019

NAHDO ends its fiscal year, September 30, 2019 in a negative financial position. NAHDO relies on multiple sources of funding to carry out its mission to improve and strengthen health care data resources Lower revenues from grants in FY 2018 and lower conference sponsorships in 2019, combined with a one-time pension liability has negatively affected NAHDO's bottom line ending in FY 2019.

	9/30/2014	9/30/2015	9/30/2016	9/30/2017	9/30/2018	9/30/19*
Revenue						
Membership	$150,208	$151,126	$138,375	$118,775	$92,000	$120,000
Grants and Contracts	$388,487	$640,399	$412,033	$200,620	$159,171	$309,697
Conferences	$119,350	$172,985	$172,985	$177,045	$173,899	$130,800
Other	$335	$848	$114	$189	$473	$694
Total Revenue	$661,597	$965,358	$730,367	$487,084	$425,543	$561,191
Total Expense	$685,093	$875,755	$709,931	$533,540	$511,001	$682,512
Gain/Loss	($23,496)	$89,603	$20,436	($46,456)	($85,458)	($121,321)
Fund Balance	$633,581	$723,184	$743,620	$697,164	$611,706	$490,385

*unaudited