

# **Annual Report**

Fiscal Year 2017

National Association of Health Data
Organizations (NAHDO)



NAHDO's purpose is to

develop and facilitate

networks of health
information professionals to:

.....Advocate for proper

protections of health information

while preserving access to such

data by the appropriate users.

### NAHDO's MISSION

The National Association of Health Data Organizations (NAHDO) is a national, not-for-profit membership organization dedicated to improving health care through the collection, analysis, dissemination, public availability, and use of health data.

NAHDO provides information on current issues and strategies to develop a nationwide, comprehensive, integrated health information system. NAHDO also sponsors educational programs, provides assistance, and fosters collaboration for the exchange of ideas and experiences. By doing so, NAHDO works to enhance the understanding of health data systems and increase the usefulness of health data.





"Today, the vision remains as relevant as it was in 1986, perhaps even more, as health care and payment reform accelerates...

We are stronger together and it is more effective and efficient when states align around common issues."

## **Executive Director's Message**

2016-2017 was a year of massive political change and drove home the importance of multi-state collaboration to address cross-cutting issues demanding a coordinated response. The NAHDO community worked together to submit comments in the federal Notices of Proposed Rulemaking (NPRM):

- -----Department of Labor
- -----SAMHSA 42 CFR Part 2 (Substance Use Data)

The power of our health data community working together was evident in development of APCD reporting standards (in response to the DOL NPRM). In May of 2016, NAHDO with the APCD Council worked with states, their vendors, and the payer community to develop a draft Common Data Layout (CDL) for State APCDs. As of June 2017, the group has completed a review and a final draft is forthcoming. While the process has not been determined, states and payers have agreed to review and make any necessary updates to the CDL on an annual basis. Engagement with SAMHSA staff has led to a productive dialogue and potential solutions which will move forward during 2017.

It is an honor to serve the NAHDO community and promote the sustainability and advancement of public reporting systems. This year we saw great strides in advancement of APCD reporting, providing actionable information on cost and utilization variation and low value services. States with APCDs can target improvements to reduce waste and costs, as well as evaluate the effectiveness of health reform and payment reforms.

NAHDO continues to promote the value of hospital discharge reporting systems which are uniquely positioned to provide population-based and system-wide information on quality, outcomes, and system performance. We were approached by ProPublica to coordinate a multi-state effort to inform consumers about select cancer surgeries—demonstrating value in the public data investments states have made.

Despite the political changes, cost and quality transparency will be a policy focus and state leadership and cross-state collaboration will be essential to meeting our missions to provide data for informed decisions.

The health care system is under tremendous pressure to lower costs and improve quality. Providers and policymakers are seeking more (data) and better data for informed choices. The sheer volume of data is expanding rapidly and the pace will only accelerate.

Your efforts are stymied by data sharing restrictions, privacy concerns, legal, and funding challenges as well as industry resistance. Thank you for the work you are doing to overcome these challenges to advance the data-driven transformation, where transparency becomes the rule—not the exception.

Excerpt from plenary video message: Sen. Sheldon Whitehouse, RI, Minneapolis, MN, October 2016.



Most useful is the opportunity to meet and hear from a variety of people who are "on the ground" doing the work needed to accelerate adoption of APCDs.

The conference is a chance to network with colleagues from other states/agencies that are grappling with big data issues, particularly the struggle between data transparency and confidentiality for patient data.

# NAHDO's 32<sup>nd</sup> Annual Meeting and 10<sup>th</sup> APCD Workshop

Beyond the Ballot: Non-partisan Approaches for Healthcare Data, Tools, & Ideas to Inform Health Policy Minneapolis, MN, October 2016

General sessions were held in conjunction with the APCD Workshop. The meeting was well attended with over 180 individuals representing 33 states, federal and private sector organizations. Innovations in the collection, analysis and release of health care were presented. Challenges and solutions related to health care transparency, consumer engagement and community health were disused.

#### **2016 AWARDS**

Elliot M. Stone Health Data Leadership Award:

Anne Elixhauser, PhD, Agency for Healthcare Research and

Quality

<u>Data Dissemination Award:</u> <u>CompareMaine</u>

All-Payer Claims Database Pioneer Award:
Al Prysunka, Milliman







#### GRANTS & CONTRACT HIGHLIGHTS

NAHDO's grants and contracts help sustain the organization and promote NAHDO's mission. All grants and contracts are aligned with NAHDO's mission and are geared to improving the health data infrastructure.

NAHDO-CDC Environmental Public Health Tracking Network
NAHDO continues to facilitate the access to and use of hospital
discharge and claims databases for creating standardized
health indicators measuring morbidity and health outcomes
related to environmental exposures. Goals for the project
include:

- Promoting access to and the use of health care data in tracking applications
- Providing education and outreach on priority topics
- · Facilitating CDC tracking program goals

# Healthcare Cost and Utilization Project (HCUP) Standards HCUP-US Partner Website Support to Partners

The Healthcare Cost and Utilization Project (HCUP) has engaged NAHDO for data standards work related to the Healthcare Cost and Utilization Project (HCUP). This work is funded through a subcontract with Truven Health Analytics under the HCUP contract. NAHDO's Data Measurement Scientist Consultant, Barbara Rudolph, Ph.D. serves as the state public health voting member on the National Uniform Billing and Claims Committees (NUBC) and (NUBC). This representation is important to promote standards that align with state administrative data practices and analytic uses.

New Mexico Department of Health & RWJF State Health Value Strategies Human Services Department: A Plan for Implementing a Statewide Health Care Cost and Quality Reporting Website in New Mexico

NAHDO was contracted to provide technical assistance to the New Mexico Department of Health to guide the work of the state health information system advisory committee and the Department of Health as they explored options and considerations for publishing data to the public, as required by law.



NAHDO is a co-leader and founder of the All Payer Claims Database Council to promote the implementation of statewide APCDs.

"The APCD Council team has been supporting Maryland's development of two new APCD reports. In addition to providing valuable technical knowledge, they leveraged their learning network of state APCD's to enrich our analysis and ability to collaborate with other states and insurance carriers."

#### **KEY PARTNERSHIPS**

#### **All-Payer Claims Database Council**

NAHDO is a Co-Leader and Co-Founder of the APCD Council. The APCD Council is a collaboration between the New Hampshire Institute for Health Policy and Practice (NHIHPP) at the University of New Hampshire (UNH) in Durham, New Hampshire, and NAHDO.

NAHDO works closely with the APCD Council to advocate for and provide technical assistance to states planning and implementing statewide APCD systems. While the Council's work is not funded (provided by in-kind services from UNH and NAHDO), the Council has received funding for specific deliverables.



### Joint Public Health Informatics Task Force (JPHIT)

NAHDO is a founding and voting member organization of the Joint Public Health Informatics Taskforce (JPHIT). JPHIT is a collaboration of public health associations committed to improving population health through informatics, health IT and information exchange, serving as a thought leader on emerging informatics issues for public health. NAHDO Board member, Patricia Merryweather, is serving with Denise Love on this task force.



"I've been part of the organization since the early 90's when working for a state health data agency. NAHDO meeting had tremendous value to me in that role. The connections I've made over the years are extremely important, and the content still has relevance although I no longer work for a health data agency."

# REPRESENTING HEALTH DATA PROGRAMS NATIONALLY

#### **Advocacy for Data Program Interests**

NAHDO continues to advocate for and represent state and health data program interests via the following:

- As Co-Conveners of the APCD, NAHDO continues to respond to media and other inquiries about APCD initiatives and to provide technical assistance and guidance to states in the form of the APCD Learning Network and individual state contracts.
- NAHDO's Executive Direct continues her appointment to a four-year term on the National Committee for Vital and Health Statistics. The 18-member Committee provides advice, consultation, and assistance and makes recommendations to the Secretary of Health and Human Services on national health information policy

## NAHDO and the APCD COUNCIL CONTINUED TO ADVOCATE FOR DATA REPORTING SYSTEMS AT THE STATE AND NATIONAL LEVELS

#### **DOL NPRM AND STANDARDIZATION**

NAHDO, UNH, and NASHP submitted comments proposing a cooperative pilot for state collect self-insured data. After months of lengthy calls between states and payers, a Common Data Layout (CDL) was developed and comments were submitted to DOL proposing to "minimize cost and burden on ERISA plans and adhere to ERISA's statutory goals of uniformity, consistent with the Supreme Court's decision in *Gobeille*". To further reduce the burden on ERISA plans, all ERISA plan data, self-funded and fully-insured, could be submitted using the Common Data Layout.

#### SUBSTANCE ABUSE DISORDERS AND 42 CFR PART 2.

States mobilized. Without access to substance use treatment data by state agencies in their robust data systems, the data necessary for effective public policy related to the key issues in substance abuse will not be available. Those individuals most in need of the focused attention of population health and health reform policy research of all kinds will be marginalized. The result will be directly contrary to SAMSHA's purported purpose in modifying 42 CFR Part 2. inpatient data on volume for select cancer conditions.

NAHDO continues its voting representation on the National Uniform Billing and the National Uniform Claims Committees (NUBC, NUCC) and X12.

NAHDO is recruiting members and experts in health care data collection, analysis, and reporting who are willing to represent NAHDO and our members in various conferences and webinars. Let the NAHDO staff know if you are interested (info@nahdo.org).

### TREASURER'S REPORT, FISCAL YEAR 2016

NAHDO'S fiscal year ends September 30, 2017. Reductions in membership and project revenues resulted in a loss during FY 2017, despite reduction in variable expenses such as consulting services. During 2018, NAHDO will work to increase revenues and manage expenses.

	9/30/2013	9/30/2014	9/30/2015	9/20/2016	9/30/2017	
Revenue					Unaudited	
Membership	\$152,042	\$150,208	\$151,126	\$138,375	\$118,775	
Grants and Contracts	\$234,427	\$388,487	\$640,399	\$412,033	\$200,620	
Conferences	\$119,350	\$122,567	\$172,985	\$179,845	\$167,500	
Other	\$146	\$335	\$848	\$114	\$189	
Total Revenue	\$505,965	\$661,597	\$965,358	\$730,367	\$487,084	
Expenses	\$430,276	\$685,093	\$875,755	\$709,931	\$533,599	
Gain/Loss	\$75,689	(\$23,496)	\$89,603	\$20,436	(\$46,515)	
Fund Balance	\$657,077	\$633,581	\$723,184	\$743,620	\$697,105	

# NAHDO Board of Directors 2016-2017

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## NAHDO gives special thanks to:

The University of New Hampshire Institute for Health Policy and Practice for their collaboration in all things APCD.

NAHDO members and supporters throughout the country who believe in the power and value of publicly available health care data bases and the importance of quality, pricing, and health system performance reporting.

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