National Committee on Vital and Health Statistics

Advising the HHS Secretary on National Health Information Policy

Access to Federal Data

Project Update

May Full Committee

May 16, 2018

Background

- Concerns raised about ease of HHS data access for community and state purposes
- Concerns raised about ease of HHS data access for research, evaluation, and dissemination
- Data needs for enabling commerce

Background

Loss of four Federal Health Data Systems: CHSI, HIW, HDI and BRFSS rollups

- Community Health Status Indicators (CHSI)
- HHS Health Indicators Warehouse (HIW)
- Behavioral Risk Factor Surveillance System (BRFSS)
- Health Data Interactive (HDI)

Issues with Data Access

- Data access changed, unclear why; is data infrastructure too costly to create or maintain?
- Data moved into Research Data Centers (RDCs) with goal to allow linkage of publicly available data with restricted data for research; feedback: it has locked up previously permissible data use
- Are there ways in which technology and statistical methods can address concerns about re-identification of data? Can HHS agencies use available methods to assess data risk for a given data set and modify it according to risk tolerance? ie, routine vs. epidemic (opioids)

Committee Questions

- Which data are no longer available?
  - Which data are no longer provided reliably?
  - Which data are more difficult to access?
- Which communities need these data, and why?
  - How were data previously used?
  - What decisions and activities did these data support?
  - Which commercial interests are affected?

Preliminary Findings--APHA

Which data are no longer provided reliably? CHSI, HDI

How were data previously used?

- Data were used by APHA members for research and to provide background information for advocacy efforts. Public health practitioners used the data to plan health programs, identify priorities for action, and for collaborations with other providers in the health system.

What decisions or activities did these data support?

- APHA members and public health practitioners used this information to plan research, determine how to approach solving public health problems, and document outcomes. Access to current, reliable data is important for public health because it enables practitioners to make decisions based on emerging health issues and to determine whether current public health initiatives are effective.

What is the impact of lack of access to these data?

- Without access to current, reliable data, the work of public health practitioners will not be as effective as it could be otherwise. For example, public health departments rely on current data to implement their programs and respond to emerging community concerns.

Preliminary Findings—University of Missouri CARES

Which data are no longer provided reliably?

- National Notifiable Disease Surveillance System (NNDSS) data by county (in HIW)
- BRFSS 3-, 5-, and 7- year rolling average estimates for selected indicators

Which data are more difficult to access?

- Age-adjusted mortality rates by state and county for population subgroups (race, gender, age group, ethnicity, etc.)
- Birth statistics (low birth weight, teen births, infant mortality rate) by county for population subgroups
- Sexually Transmitted Infection prevalence/incidence rates by county
- Chronic conditions data for Medicare Beneficiaries by county

Which communities need these data, and why?

- CARES used this information for many projects and public access sites. These activities potentially impact communities nationwide.

Preliminary Findings—University of Missouri CARES

How were data previously used?

- Data were downloaded directly or via API and used by the University of Missouri in numerous mapping and reporting applications for both sponsored projects and open public access.

W**hat decisions or activities did these data support?**

- HIW data supported a large number of community health needs assessments, which are used by hospitals associations, community action agencies, and other organizations to identify needs and prioritize them for resource allocation.
- The following projects and applications specifically utilized Health Indicators Warehouse data:
  - CHNA.org, a free web-based reporting system supporting the community health needs assessment requirements of non-profit hospitals and hospital associations across the country
  - Other Hospital & Health Association CHNAs: Kaiser Permanente, Adventist Health System, Adventist, Providence St. Joseph, American Heart Association (AHA) Assessment Report, Community Action Agency Needs Assessments, New York, Pennsylvania, Missouri
  - University of Missouri Extension Assessment Reports
  - Various index and rankings projects

Preliminary Findings—SGIM Research Committee

Data that were in the process of being made available previously have now also been taken off the block.

For instance, we had been working with CMS to obtain the RAPS data (the risk adjustment data used to pay Medicare Advantage plans) for over a year and they pulled back

Similar is the availability of the Medicare Advantage encounter data (see the recent viewpoint by Austin Frakt and Niall Brennan on this JAMA. 2018;319(10):975-976)

NOTE: CMS announced release of MA data at Datapalooza 2018

Preliminary Findings—Community Hospital Corp

The Community Health Status Indicator (CHSI) peer county data offered through the CDC, now discontinued, was one of our most useful data visualizations for our Community Health Needs Assessments (CHNAs).

The organization for which I work is engaged with mostly rural communities, which generally limits data collection and analysis due to smaller population numbers and statistical unreliability/inaccuracy.

The peer county data offered by CHSI through the CDC was very appreciated by our rural hospitals who struggle to find an "apples to apples" comparison point when we portray their data as compared to the state, or to any nearby counties that are not as compositionally similar.

Peer county data allowed for the hospitals that we work with to see where they stand as compared to counties that have similar backgrounds - thus giving them more perspective on what their true community needs are in developing their 3 year implementation plan.

Preliminary Findings—Trilojy Integrated Resources, LLC

- Trilojy is active in 27 states (soon to be 29, with Florida and Massachusetts). We host more than 700 local websites, of which more than 250 are local public health sites (you can see the list and visit the websites here).
- We developed our public-health websites after HHS deployed the Data Warehouse and made the data available for the first time, making it possible to deliver this service at a reasonable cost to our clients. However, since last August, we've been struggling with access to many of these indicators. As a result:
  - timeliness and quality of our service is compromised
  - our clients have to partner with us to locate the data locally, otherwise we simply are not able to provide the information to them and their stakeholders
- **Which data are no longer available?** 219 data elements from National Vital Statistics System-Mortality & Natality, BRFSS (county), Chronic Condition Data Warehouse
- **Which data are more difficult to access?** Chronic conditions and BRFSS.
- **Which communities need these data, and why?** 256 local health districts in 20 states.

Preliminary Findings—Trilojy Integrated Resources, LLC

- **How were data previously used?** We provide a comprehensive list of health indicators at the local level, as well as access to best practices and other third-party content associated with each indicator, using Data Warehouse keywords and tags attached to each indicator ID.
- **What decisions or activities did these data support?** County and local governments use this data to assess the overall health of their communities. At times, they use it for their certification process. Local providers and other stakeholders use this data to prepare grants and identify issue areas that need their attention.
- **What is the impact of lack of access to these data?** That is hard for us to measure, at this point, but it is likely that we will need to raise our prices, and some data may not be available even then.
- **Which, if any, commercial interests are affected?** Obviously, higher prices make it difficult for our clients to adopt the product. We have had to completely change our back-end infrastructure; as a result, we've invested more than a quarter of a million dollars in rebuilding the entire application to respond to the new schema. This effort has consumed a small team of employees and a large team of consultants for the past six to seven months.

Data Access

Next Steps

Workplan

	2018 Q1	2018 Q2	2018 Q3	2018 Q4
HHS data access	Preliminary fact-finding activity Obtain perspectives from data users, stakeholders	• Preliminary Summary of Findings • Discuss with FC May meeting • Scope project • Environmental Scan?	• Convene Hearing • Environmental Scan?	• Fact finding summarizing • Develop recommendations