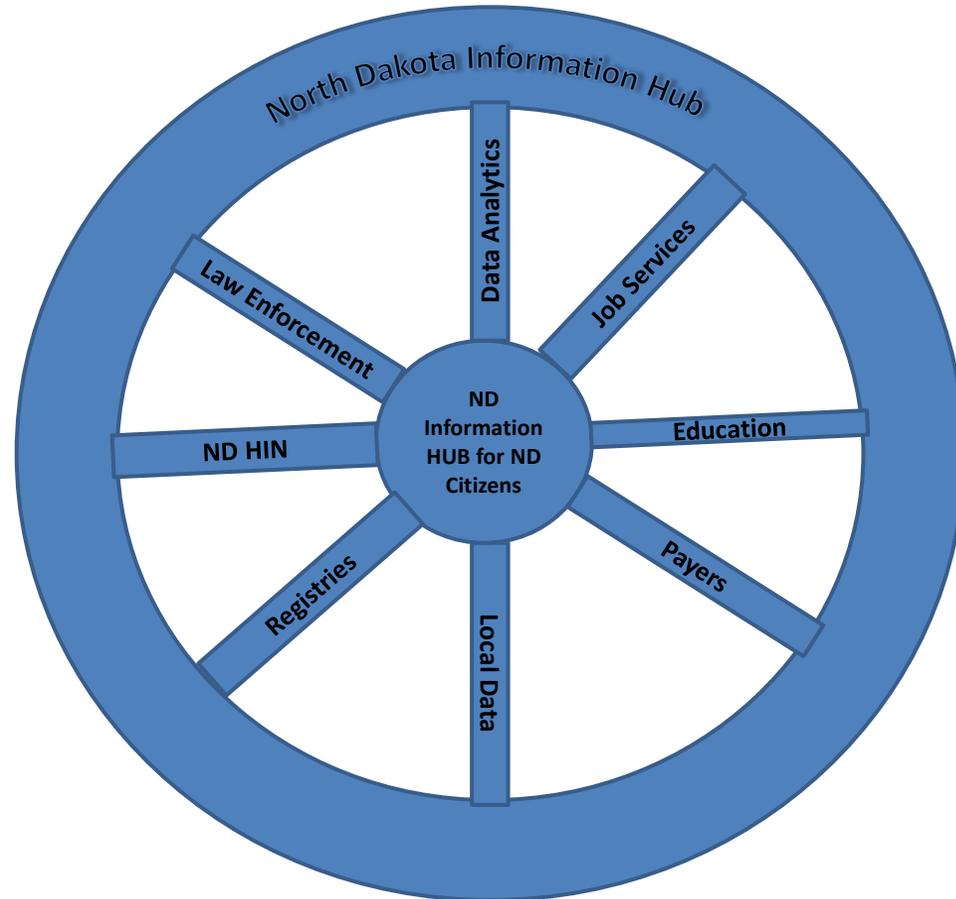


Sheldon Wolf

ND Health IT Director



North Dakota Information Hub



- Privacy, Confidentiality and Security are **key** initiative **priorities**

House Bill 1021

SECTION 3. HEALTH DATA STUDY - REPORT TO INFORMATION TECHNOLOGY COMMITTEE.

The health information technology office line item includes the sum of \$500,000, from special funds, federal funds, or other funds, for the purpose of hiring a consultant to provide a health data study, for the biennium beginning July 1, 2015, and ending June 30, 2017. Before July 1, 2016, the information technology department shall report the findings of the consultant to the information technology committee.

Status

Unable to obtain funding --- UND took on the task of obtaining the information

Use Cases

North Dakota

- The Opioid / Fentanyl Crisis in North Dakota
- Syndromic Surveillance Data
- Mental Health / Substance Abuse

Goals of Project

1. Identify existing state health data centers that may serve as models for North Dakota (Environmental Scan).
2. Develop detailed information about the potential model state health data centers.
3. Identify the health data needs of North Dakota stakeholders.
4. Develop an information hub proposal for legislators that meets stakeholder health data needs.
5. Conduct a pilot project to demonstrate the usefulness of an information hub.

Status

UND School of Medicine and Health Sciences (Goal 1 & 2)

- MPH Program scanned other state's data centers
- Conducting in-depth study with select states data centers

Website Scan Results

- Stakeholders that data centers aim to serve can include:
 - Policymakers at the state and local levels
 - Interested public Health care professionals
 - Private industry
 - Researchers

(See handout)

Website Scan Results - Stakeholders Priorities

The state's healthcare system

- Access to healthcare
- Utilization of healthcare
- Quality (effectiveness) of healthcare
- Cost of healthcare

The health status of the state's residents

- Prevalence of various health problems
- Trends in health problems
- Disparities in health status

The social, behavioral, and environmental determinants of health in the state

- Prevalence and trends in employment and poverty
- Prevalence and trends in educational attainment
- Trends and prevalence in behaviors that promote health
- Trends and prevalence in behaviors that impact health adversely

The state government's services

- Utilization of health and social services
- Quality (effectiveness) of health and social services
- Cost of health and social services
- Access to health and social services

Identify the health data needs of North Dakota stakeholders. (Goal 3)

- Center for Rural Health interviewing stakeholders
- Questions around:
 - Need and timeliness of data
 - What type of data needed
 - Parameters of the Hub
 - Access to data

Develop an information hub proposal for legislators that meets stakeholder health data needs. (Goal 4)

Conduct a pilot project to demonstrate the usefulness of an information hub. (Goal 5)

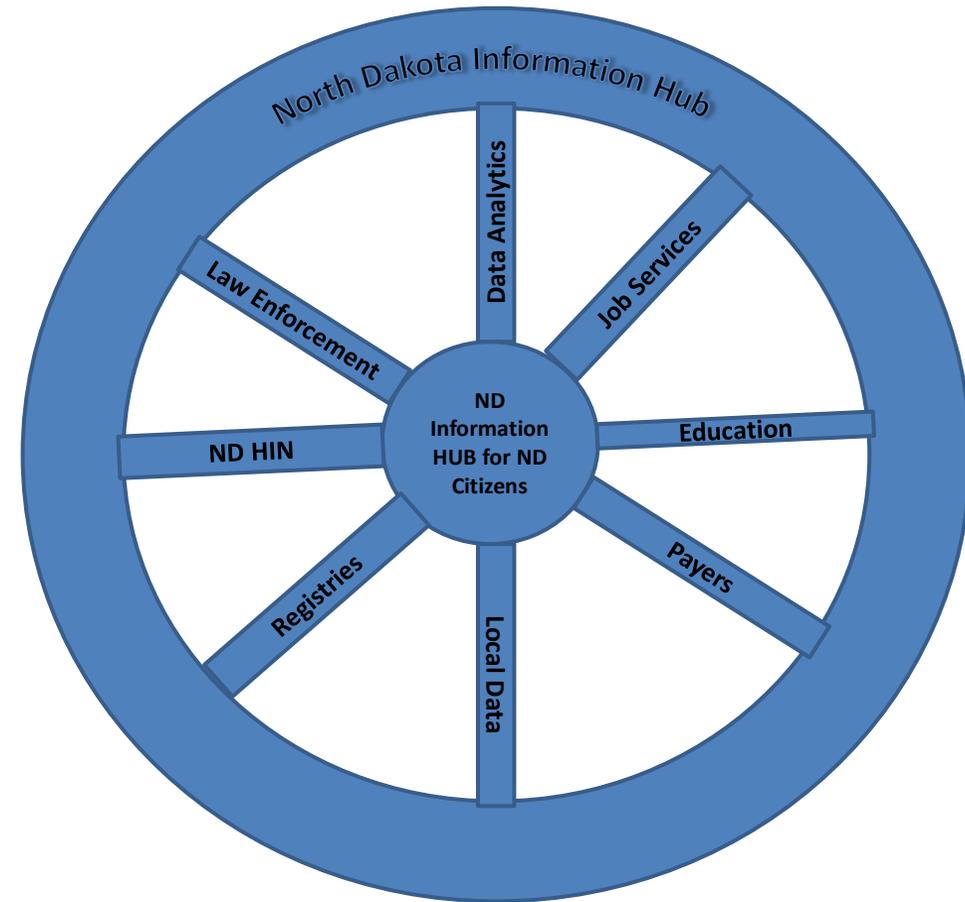
Goal 4 & 5 – will be started upon completion of Goals 1-3

Rhode Island Example

Rhode Island -- <http://ridatahub.org/datastories/>

- High School Chronic Absenteeism & College Persistence: Linking K-12 data to Post-secondary outcomes -- <http://ridatahub.org/datastories/high-school-absenteeism-college-persistence/1/>
- Which schools have high numbers of students at risk of involvement with the juvenile justice system, and how can data help these schools and others manage the risks? <http://ridatahub.org/datastories/an-early-warning-story/3/print>
- <http://ridatahub.org/>

Questions?



Privacy, Confidentiality and Security are **key** initiative **priorities**

Summary Report on State Health Data Centers

Prepared for:
Executive Committee
North Dakota Health Information Hub

By:
Information Hub Support Team
UND School of Medicine & Health Sciences

Overall Project Goals for North Dakota Health Information Hub:

- Goal 1: Identify existing state health data centers that may serve as models for North Dakota (Website Scan)
- Goal 2: Develop detailed information about the potential model state health data centers
- Goal 3: Identify the health data needs of North Dakota stakeholders
- Goal 4: Develop an information hub proposal for legislators that meets stakeholder health data needs
- Goal 5: Conduct a pilot project to demonstrate the usefulness of an information hub

Website Scan: Methods

Scanned websites of state health data centers that were members of the National Association of Health Data Organizations (NAHDO) in September 2015

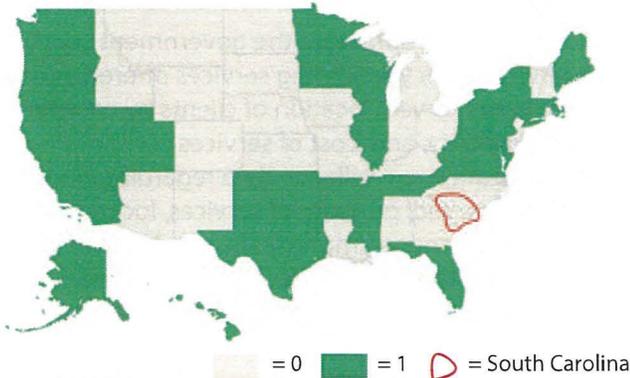
- 49 participating NAHDO members
- 25 non-state based agencies
- 24 state-based agencies

Selected the 24 organizations that were state-based

Alaska, Arkansas, California, Connecticut, Florida, Hawaii, Illinois, Maine, Maryland, Massachusetts, Minnesota, Mississippi, Nevada, New York, Oklahoma, Oregon, Pennsylvania, Tennessee, Texas, Utah, Virginia, Washington, West Virginia, Wisconsin

Added other state organizations, ad hoc, when discovered through website scan:

- South Carolina
- Connecticut Data Collaborative



Questions guiding website scan

- What is the mission of the data center?
- What data does the data center house?
- What is the source of the data?
- What questions can be answered with the data?
- Who has access to the data?

Website Scan: Results

Great variation in state data centers

Each one is unique

What explains the variability?

Data centers respond to stakeholder values and priorities

What do stakeholders want to know about health?

What are their concerns?

What questions do they want to answer?

Stakeholder values and priorities determine:

What data systems are contained in the center

How and to whom information is distributed

Technology decisions follow from these decisions

Software and hardware

Staff size and qualifications

Stakeholder priorities can be categorized as:

The state's **health care system**

The **health status** of the state's residents

The **social, behavioral, and environmental determinants of health in the state**

The state **government's services**

Website Scan: Results, continued

Categories of stakeholder priorities: **health care system**

- Access to health care
- Utilization of health care
- Quality (effectiveness) of health care
- Cost of health care

Data systems for **health care system** often include:

State inpatient, emergency department, and outpatient data

Source: State agency that collects discharge and outpatient data

American Hospital Association (AHA) survey

Source: State agency that collects survey information for AHA reporting

Healthcare Cost and Utilization Project (HCUP) data

Source: Agency for Healthcare Research and Quality (AHRQ)

An overview of HCUP is available at:

<http://www.hcup-us.ahrq.gov/overview.jsp>

Categories of stakeholder priorities: **health status**

- Prevalence of various health problems
- Trends in health problems
- Disparities in health status

Data systems for **health status** often include:

State disease and injury registries

Source: State agencies, usually state department of health

Can include cancer, stroke, tumor, STD/HIV, trauma, and others of interest

Vital statistics records: birth, death, marriage, divorce records

Source: State Bureau of Vital Statistics

Health Indicators Warehouse

Source: CDC National Center for Health Statistics

Serves as the data hub for the HHS Community Health Data Initiative, a flagship HHS open government initiative to release data

See for more information: <http://www.health-indicators.gov>

Categories of stakeholder priorities: **social, behavioral, and environmental determinants**

- Prevalence and trends in employment and poverty
- Prevalence and trends in educational attainment
- Trends and prevalence in behaviors that promote health
- Trends and prevalence in behaviors that impact health adversely



Data systems for **social, behavioral, and environmental determinants of health** often include:

Behavioral Risk Factor Surveillance Survey (BRFSS)

Source: CDC

Youth Risk Behavior Surveillance Survey (YRBSS)

Source: CDC

Health Indicators Warehouse (see Health Status)

Source: CDC National Center for Health Statistics

National Survey of Drug Use and Health (*state estimates only*)

Source: Substance Abuse and Mental Health Services Administration (SAMHSA)

State conducted surveys

Source: State Departments of Health and/or Social Services

U.S. Census Bureau and Bureau of Labor Statistics data

Categories of stakeholder priorities: **state government services**

Utilization of health and social services

Quality (effectiveness) of health and social services

Cost of health and social services

Access to health and social services

Data systems for **state government services** often include:

Administrative data from the government social service agency regarding services offered, number of clients served, location of clients by county/municipality, and cost of services

Immunization surveillance data regarding number of clients served, provider of services, location of clients by county/municipality, and cost of services

Sources for these data systems are the state government agencies themselves

State data centers also vary in **comprehensiveness**

The range in number of data systems is enormous. One of the most comprehensive data centers is in

California

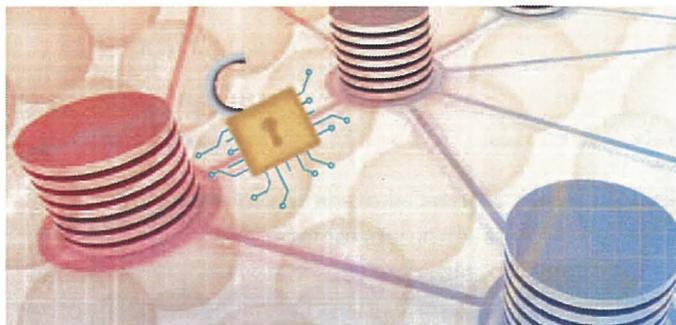
11 publishing Departments

See California Health and Human Services Open Data Portal: <https://chhs.data.ca.gov/>

Website Scan: Results, continued

Stakeholders that data centers aim to serve can include all or some of the following:

- Policymakers at the state and local levels
- Interested public
- Health care professionals
- Private industry
- Researchers



There are 2 basic levels of access given to stakeholders:

Restricted:

- Only data center staff has access to data
- Staff analyze data and provide reports
- Reports may be prepared routinely and by special request
- Reports may (or may not) be available on website in pdf form
- Raw data may (or may not) be available upon request and approval of staff

Open:

- Stakeholders have access to all information and data that do not compromise privacy rights of individuals or organizations
- Data queries and data downloads are available
- Raw data has been structured for queries
- Structured data can usually be downloaded
- Raw data cannot be download
- Example: CDC Wonder's mortality data query system

Interactive, which allows stakeholders to search for information and obtain what is relevant for them

Open government and state data centers:

The 'open government' value guides some some state data centers

10 states currently have open data policies:

Connecticut, Hawaii, Illinois, Maryland, New Hampshire, New York, Oklahoma, Rhode Island, Texas, Utah

Open data policies defined:

Open data policies 'require basic government data, such as expenditure information, as well as other agency data, to be published on their open data portals in machine-readable format.'

'Open data portals bring data from multiple government agencies onto a single website.'

Goals of Open Data:

- Encourage transparency and accountability
- Increase public participation
- Promote economic growth

Benefits of Open Data:

'A 2013 McKinsey Global Institute report estimated that open data could add over \$3 trillion annually in total value to the global economy.'

Open Data policies are established by:

- Governors or state legislatures policies
- Executive orders: Connecticut, New York, Rhode Island

Software for sharing data interactively on the web is exploding

Application Program Interface (APIs)

Software used for some open data portals

SOCRATA, a cloud-based software for states with goal of open data

Examples of states that use SOCRATA include California, New York, Utah

See for more information:

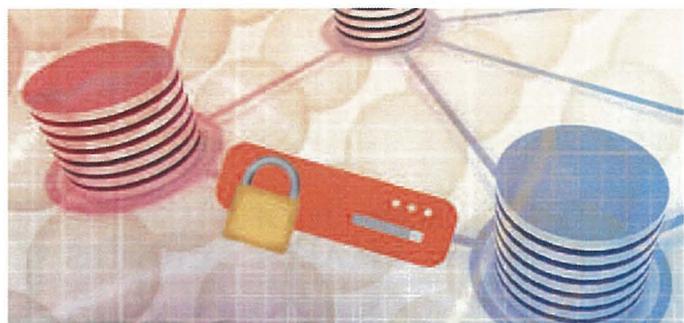
<https://www.socrata.com>

CKAN, another open data software, which is free

Example of states that use CKAN include

Connecticut Data Collaborative

See for more information: <http://ckan.org>



Website Scan: Summary

Once a state data center articulates what stakeholders want to know and what kind of access stakeholders will have, the design of the data center falls into place

- Data systems are identified
- Resources are specified
 - Staff, Software, Hardware
- Organizational issues are decided
 - Location, Structure
- Source of funding is identified

A state data center is not a static endeavor

- Continuous improvement of both data and access for stakeholders
- Technology moving very fast
- New technological capabilities will continue to be developed
 - Independent of what stakeholders *want* to know
 - Although it structures what stakeholders *can* know
 - If you dream it, it will happen
 - For example, link persons across all state service systems to improve efficiency
- Change will be on decision map in the future

Next Steps:

Goal 2: Develop Detailed Information about Potential Model Centers

- Conduct telephone interviews with directors
 - Confirm center purpose, users, budget, staffing, source of funding, sustainability, perceived benefits, lessons learned
- Conduct telephone interviews with chief information officers
 - Develop information about technical aspects including processes and policies regarding data transfer, validation, storage, security, sharing, and other technology issues

For more information, please contact:
Raymond L. Goldsteen, DrPH
Director, MPH Program
Professor, Department of Population Health
School of Medicine & Health Sciences
University of North Dakota
501 N. Columbia Road, Stop 9037, Room 2370H
Phone: 701.777.2375, Fax: 701.777.0980
Raymond.goldsteen@med.und.edu



Goal 3: Identify North Dakota Stakeholder Needs

Identify 10-15 stakeholders for interviews

- Legislators, health care providers and payors, public agency personnel including DOH and DHS, other
- Conduct a personal interview with each
 - What do you and your organization need to know about health and health care in North Dakota?
 - What have you wanted to know, but couldn't find out? Where do you get your information now?
 - What opportunities do you see for improving access to health information for stakeholders such as yourself?