SECRETARY’S ADVISORY COMMITTEE, REPORT #9

RECOMMENDATIONS FOR BUILDING A DATA PARTNERSHIP INFRASTRUCTURE FOR HEALTHY PEOPLE 2030

Submitted to the Secretary of the U.S. Department of Health and Human Services
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I. FOREWARD TO THE SECRETARY’S ADVISORY COMMITTEE ON HEALTHY PEOPLE 2030

Community-level information, together with national, tribal, state, territorial, and local data, will enable accountability, surveillance, and effective decision-making. The Advisory Committee presents these 4 recommendations as actions to support programs and policies to meet Healthy People 2030’s objectives.
II. INTRODUCTION

The Secretary’s Advisory Committee on National Health Promotion and Disease Prevention Objectives for 2030 (the Committee) is a federal advisory committee composed of non-federal, independent subject matter experts. It is responsible for making recommendations to the Secretary of the U.S. Department of Health and Human Services (HHS) on the development and implementation of national health promotion and disease prevention objectives for 2030.

After its inaugural meeting in December 2016, the Committee appointed several subcommittees, charging each to provide guidance on aspects of the initiative’s development. The Data Subcommittee was charged to identify data requirements for Healthy People 2030 and to fulfill core functions of Healthy People, enable assessment of trends, and manage efforts to achieve the objectives. Data requirements for Healthy People 2030 include basic requirements (data needs, data source standards, and progress reporting) and innovation related to data (changes in data sources, analysis and reporting, community data, summary measures, and the future of health data). The Data Subcommittee has offered guidance to the full Committee on identifying data needs and recommending principles and methods to guide target setting for Healthy People 2030.

The full Committee met 15 times (3 times in person and 12 times via webinar) to discuss, revise, vote upon, and finalize recommendations to the Secretary. At its September 2018 meeting, the Committee opted to reconvene the Data Subcommittee, tasking it to draft recommendations for the Committee’s eighth report (titled Recommendations for Implementation and the Framework Graphic) on structuring data partnerships at the state and local levels. The subcommittee offered guidance to ensure that local data that are included in Healthy People 2030 meet data standards, and to help states and localities meet data quality standards. The subcommittee submitted its recommendations to the full Committee in February and June 2019. A central theme of the subcommittee’s discussions was that Healthy People 2030 should use community data, as summarized below:

To support programs and inform policies to meet the objectives, data specific to the community are needed. HHS should work with communities to frequently (e.g., every quarter) update community-level information (e.g., numerical data, observations that community members are making about progress or barriers). Community-level information should be used together with national, tribal, state, territorial, and local data to enable accountability, improvement, surveillance, and decision-making.

This current report (#9) is based on ideas that were raised during the Data Subcommittee’s deliberations between October 2018 and January 2019 and developed more fully in subsequent meetings between July and October 2019. In October the Committee reviewed, discussed, and voted to approve the recommendations that are presented in this report.
III. RATIONALE FOR THE DATA PARTNERSHIP INFRASTRUCTURE AND NETWORK

High-quality data are central to the Healthy People initiative, and Healthy People objectives are based on such data. (A diagram modeling the roles and impact of data in Healthy People is included in Appendix A.) Because Healthy People objectives are built on high-quality data, users know the objectives give an accurate measure of the nation’s current health and well-being. The objectives also help to estimate how that measure might improve over the decade. Past editions of Healthy People have linked objectives primarily to national data sources that represent the entire population of the United States.

For the current decade, the Committee has emphasized that it is important for the Healthy People objectives to link to data at the tribal, state, territorial, and local levels in addition to national data. These additional levels of data are critical because interventions to improve population health are most commonly implemented and evaluated at these levels. Thus, data at the tribal, state, territorial, and local levels are highly relevant to stakeholders who are working at levels that are more local than national.

Data pose challenges and opportunities at all levels. Healthy People 2030 can help organizations at each of these levels to deal with data issues such as assessing data quality, applying appropriate analysis methods, and identifying new data sources. A national network of data partnerships can create an underlying foundation for high-quality data at all levels and promote shared learning about priorities, opportunities, and challenges. This Data Partnership Infrastructure and Network will enable Healthy People partners to best respond to new developments in data sources and data analytics. In this report, the Committee describes how a Data Partnership Infrastructure and Network might function.
IV. PURPOSE AND FUNCTION OF THE DATA PARTNERSHIP INFRASTRUCTURE AND NETWORK

The Committee envisions that the Data Partnership Infrastructure will comprise a national network of entities that are committed to the Healthy People 2030 framework, and that already address, or are poised to address, Healthy People goals and objectives. Other potential criteria for organizational participation in the network include an organization’s willingness or capacity to:

- Collect data according to agreed-upon measurement frameworks and data definitions.
- Share data.
- Use or modify existing data collection, storage, and analyses in a way that follows the guidance for Healthy People data.

The ultimate goal of the network is to expand the availability of quality data and data analytic capacity to those who oversee and implement programs and efforts to achieve Healthy People objective targets. Specific goals for the Data Partnership Network are to:

- Create or expand the availability of locally relevant data.
- Improve the capacity of all partners to meet the data-related recommendations of the Secretary’s Advisory Committee for Healthy People 2030.
- Implement the Healthy People 2030 Framework framework (Vision, Mission, Foundational Principles, Overarching Goals, Plan of Action) to ensure the availability of high-quality data on health and well-being, health equity, and the determinants of health.
- Identify local data that may highlight equity issues that could otherwise be buried and hidden if only national data were used.
- Stimulate access to new data sources to measure the determinants of health and health equity.
- Enable linkage of geographic and demographic data in formats that Healthy People stakeholders can readily use.
- Obtain insights for small-area estimation and data needs that can be used for local action.
- Have the ability to measure, target, and monitor effects of single and combined interventions more effectively and efficiently.
- Enable the Healthy People initiative to take advantage of advances in data and data science, while maintaining necessary standards of quality. This would assure the public that the initiative continues to offer high-quality information and rigorous analysis, and that privacy and confidentiality issues are well met.
By participating in the network, partner organizations would be able to share data, methods, and analyses with one another, and to access guidance on data and data developments that are relevant to implementing Healthy People 2030. Such guidance could include insights into related organizational, data management, and analytic issues. Guidance could support the Healthy People 2030 developmental and research objectives, as well as the core objectives. In this manner, partner organizations would benefit by gaining access to cutting-edge information from HHS and from their peer organizations. The Healthy People 2030 initiative would benefit by gaining access to data at the tribal, state, territorial, and local levels that, over time, could help to offer more granular, relevant, and timely information on measures of the U.S. population’s health.

The Committee has identified several needs for the Data Partnership Infrastructure and Network at its inception. These include strategies and mechanisms for sharing data and analytics in order to:

- Stimulate further development of data analytics for entities that work at different levels (i.e., tribal, state, territorial, or local) and Healthy People 2030 topic areas.
- Contribute to the monitoring and progress of the Healthy People 2030 initiative.

Examples of approaches to sharing data and analytics include:

- Receiving guidance from the federal level
- Sharing analytic methods among partners
- Sharing visualization techniques among partners
- Pooling data (with assurance of data quality and protection of privacy)
- Managing database linkages and approaches to synthetic estimation
V. KEY POINTS

Through extensive discussions of the full Committee and Data Subcommittee, as well as invited presentations from experts, key points on data and data use at the national and community levels were clarified. Presenters included Dr. Soma Stout representing Well Being in the Nation (WIN); Dr. John Lumpkin of the Blue Cross and Blue Shield of North Carolina Foundation, representing Digital Bridge; and Mr. Richard Klein, a consultant to the National Center for Health Statistics (NCHS).

1. Measures and goals at the national level should be relevant and functional locally.
2. Achieving improved health and well-being at the local level requires that organizations from different sectors work together on issues that they believe are important in their community.
3. Achieving local or community-level change requires hyperlocal data and evidence-based tools for analysis. (Hyperlocal information focuses primarily on the concerns of the population in a community.) Opportunities to learn from and share information with other communities are also needed.
4. Communities will need technical assistance to develop, access, and use new data sources and tools (e.g., for target setting and data analysis).
5. Current work on the Digital Bridge, 100 Million Lives, and other initiatives shows that sharing information across communities is possible and important, both within the health care sector and with non-health partners. Identifying the impact of climate and environmental changes on human health is another area that could benefit from the recommended data partnerships.
6. The potential exists for data availability at the local level to significantly expand in the coming decade. For example, it may be possible to generate hyperlocal data for improvement of health and well-being by linking health data with a variety of non-health data that are relevant at the local level. Broadening the scope of such information to include local-level data (e.g., food, grocery stores, health insurance) provides more information about burden, need, and impact. Local data can also reflect activity within the social services, capturing the broader aspects of health promotion.
7. When analyzed within and across a defined geographical area, new data sources will make it possible to identify population groups residing within larger, affluent populations who are actually living in poverty. Techniques are emerging for targeting individuals at the local level with information to improve their health and health literacy, and to influence how they think about and improve their health and well-being.
8. Five of the 8 major sources of data for Healthy People include data at the state or local levels that could be important for local health improvement (https://www.healthypeople.gov/2020/data-search/Data-Sources). There is interest at the state level in combining datasets across disciplines. State-level Health Information Exchange (HIE) efforts have highlighted the need for standardized data systems that enable datasets to talk to one another. National-level leadership is needed to build a common platform that is capable of capturing data that are critical to health and well-being.
9. State-based data sources exist (similar to the Behavioral Risk Factor Surveillance System) that could be tested or adjusted for comparability to national sources and used to enhance data at the local level.

10. Data from administrative sources (e.g., USALEEP project, Medicare, Medicaid, housing, air quality) are being made available. Such data could be used to create hyperlocal data, especially for subpopulations.

11. Hyperlocal data (i.e., data focused primarily on the concerns of the population in a community) could be enhanced by partnering with projects that focus on subnational data, such as the California Health Interview Survey.
VI. CHALLENGES AND OPPORTUNITIES

As noted in the previous section, the full Committee and the Data Subcommittee have discussed the broad scope of data needs for Healthy People 2030. Data sources and forms of information (e.g., electronic health records and information gleaned from social media) are rapidly expanding. To meet the goals of Healthy People, data efforts are needed at the national, tribal, state, territorial, and local levels, and with subpopulations. More than health data alone are needed to promote the health and well-being of all people, address determinants of health and health equity, and monitor social, physical, and economic environments. Climate and environmental changes are increasingly impacting health and represent health determinants that would benefit greatly from the sharing of data and analytics. Achieving health and well-being is a shared responsibility that is distributed across levels and sectors. All of these factors, and others, form complex systems (“interdependent relationships”) and would benefit from the application of complex systems science. (See Complex Systems Science and Modeling Issue Brief, Secretary’s Advisory Committee on Healthy People 2030, https://www.healthypeople.gov/sites/default/files/HP2030_Committee-Combined-Issue%20Briefs_2019-508c.pdf).

A Data Partnership Network would be just one element in the much broader data strategy movement that is underway. For example, the federal government has drafted a Federal Data Strategy Action Plan. The mission of the Federal Data Strategy is to maximize the value of federal data for mission, service, and the public good by guiding the federal government in practicing ethical governance, conscious design, and a learning culture. (See https://strategy.data.gov/.) There is also a need to compare health and well-being and health interventions on an international scale. The Data Partnership Network concept is proposed as a step to support Healthy People in meeting these data challenges and opportunities.
VII. RECOMMENDATIONS

The figure above depicts the relationship between key elements of these recommendations. The Data Partnership Infrastructure and Network are supported by resources targeted for the data aspects of Healthy People, including the Data Partnership Network, and focus on collecting and analyzing local data. The Learning Collaborative will serve as an informational feedback loop from the implementation of Healthy People to leadership at all levels and back to the field.

It has been understood from the beginning of the Healthy People initiative that efforts at the tribal, state, territorial, and local levels are essential to national progress. Although high-quality national data remain the centerpiece of the initiative, access to and use of hyperlocal data specific to these levels are not readily available. Expertise in data standards, design, and analysis at these levels is essential but limited. Each decade, HHS entities, the Office of Disease Prevention and Health Promotion (ODPHP), and NCHS play key roles in documenting, analyzing, and reporting on data findings for objective targets. In the past, these federal entities have provided enhanced, data-specific technical assistance and collaborations to state and consortium partners. This is particularly important, since demands for and the availability of health-related data have increased exponentially at these levels. For example:

- The ACA stimulated nonprofit hospitals to conduct periodic community health needs assessments as a way to maintain their status.
- Voluntary public health accreditation of health departments, launched in 2011 as part of the National Public Health Improvement Initiative, also contributed to an emphasis on data quality use and improvement.
- Changes in health care reform, particularly the shift from volume- to value-based care and the “triple aim,” have further emphasized the need for high-quality data to assess population health outcomes as well as patient satisfaction and costs of care.
- State health insurance exchanges, which have faced some challenges, offer one example of how the proposed data partnerships could help to address such issues in the future. That is, the data partnerships can provide a forum in which facilitating factors such as interoperability, consistency, and communication can be developed and tested among key partners.
- National health reports, such as County Health Rankings and Roadmaps (CHRR) and America’s Health Rankings, have emerged. With its health data, CHRR provides state and local-level data and enables comparisons among geographic units based on data from multiple sectors, including health.

These data demands and related activities do not directly align with Healthy People objectives, but they could enhance data contributions and support for Healthy People.

Multiple efforts are creating new opportunities to assess health and well-being. Innovations in data relevant to health and well-being are revealing the potential to use a broad range of data sources to assess population health and well-being. These efforts
could inform new platforms for national surveillance systems and future ways to monitor national progress.

**Recommendation 1: Increase resources to HHS entities ODPHP and NCHS to provide guidance to tribal, state, territorial, and community stakeholders.**

Examples include:

- Establishing data baselines needed for high-priority developmental and research objectives
- Increasing resources to enhance sampling of existing national surveys, or of state-based surveys coordinated nationally to include data for targeted population groups
- Designing data standards and surveys that can be applied at these levels

This first recommendation is aimed at enhancing data at all levels to enable each level to assess how the Healthy People objectives can be most effectively addressed, and progress evaluated.

**Recommendation 2: Establish a data guidance group to identify major tribal, state, territorial, and local data needs.**

To identify and refine the Healthy People initiative’s identification and understanding of needs at the national, tribal, state, territorial, and local levels for data and analysis tools, information must be drawn from these levels. Several insights from the previous section of this report refer to these needs. This second recommendation proposes a mechanism for identifying such needs.

**Recommendation 3: Establish a Data Partnership Network and an associated infrastructure to enable those developing and analyzing data at all levels to share data and expertise in support of Healthy People 2030.**

This third recommendation is most central to this report. It proposes to create a network of partnerships (a Data Partnership Network) that aligns existing and growing population health efforts with those pertaining to Healthy People objectives. The Data Partnership Network, as a collective, permits and facilitates sharing of new approaches to enhance the role of data for Healthy People. In Appendix B, the Committee suggests the following 6 steps to develop the network:

(a) Refine the network concept: convene a Data Partnership Network Development Group.

(b) Suggest Data Partnership Network members.

(c) Consider key criteria and operating principles for developing a Data Partnership Network.

(d) Review examples of data-related partnerships.
(e) Consider additional examples focused on data entities, health data organizations, and applications that are similar to Healthy People.

(f) Establish a funding mechanism to ensure that this effort is adequately resourced.

Recommendation 4: Create a Healthy People Data Partnership Learning Collaborative

- Innovations in data for health and well-being are revealing the potential to use health care administrative data and electronic health records to estimate population health needs (e.g., Digital Bridge) for public health and private health systems.
- This recommendation would ensure that Healthy People stakeholders are at the forefront of these data explorations so they can take early action to adopt and adapt use models as appropriate.
- It is especially important that academics be an integral part of the Collaborative. This can ensure that new results from research are transmitted to the field and included in curricula, and that issues raised in the process of applying Healthy People are considered for research.
- Health information exchanges, insurance companies, and others are investing in ways to manage health and social service data, and are providing real-time feedback (e.g., to providers and health care system administrators).
- Targeted and strategic work is underway to enhance measures of well-being (e.g., 100 Million Healthier Lives), which is relevant to the Healthy People 2030 framework.

The Committee’s final recommendation aims to provide a feedback loop from the Data Partnership Network to Healthy People leadership and to the network members.
APPENDIX A. HEALTHY PEOPLE 2030 DATA GRAPHIC

**Purpose:** This graphic shows relative influence and relationships between data and the activities and components of the Healthy People program.

The influence diagram highlights the following relationships:

- Healthy People 2030’s **Mission, Vision, and Guiding Principles** have been used to develop Healthy People 2030’s **Goals and Objectives**.
- These, in turn, lead to **Data Collection** for the Healthy People objectives. The collected data are represented by **Data**. **Data collection** takes place according to **Data Standards** linked in turn to data sources and the Healthy People data repository.
- **Goals and Objectives** drive the formulation of the **Summary Measures**, which in turn are a component of progress assessment (**Assess Progress**), which leads to the **Reporting** of progress.
- **Reporting** drives the development of Programs, Policies, and Practices which, in turn, report on their activities (**Reporting**).
- **Analytics** are used to **Assess Progress** and develop **Data-Driven Statements to Guide Action**, leading to summary statements of **Impact**.
- **Community Programs and Use** represents actions in the community to meet the objectives from which **Progress is Assessed, and results reported**. **Local Data Sources** are used by the community programs to formulate strategies and assess progress.
- **National Data Partnerships** can drive **New/Alternative Data Sources** and the development of Local Data Sources. Extensive communication between these data sources and Healthy People’s data repository (**Data**) stimulate the development of new sources and ensure data quality.

**Brief Descriptions of the Boxes**

- **Assess Progress**: The process of using data to assess progress toward the objectives’ targets
- **Analytics** (also termed **Analysis**): Linking analysis of the data to interventions to evaluate progress or develop intervention plans to meet the objectives
- **Community Programs and Use**: Communities using interventions, data, and analysis to meet the objectives
- **Data**: The database holding data on the objectives—currently DATA2020. A possible expansion of this database would hold information on proven interventions for each objective
- **Data Collection**: The process of collecting data on the objectives
- **Data-Driven Statements to Guide Action**: Intervention programs based on current progress
- **Data Standards**: The data quality criteria that data sources tracking the objectives must meet
- **Goals and Objectives**: The Healthy People 2030 goals and objectives
- **Impact [Statements]**: Statements assessing the impact achieved by the objectives
- **Local Data Sources**: Data sources specific to a locale and/or target group
- **Mission, Vision, and Guiding Principles**: The driving forces in developing and prioritizing the objectives and interventions
- **National Data Partnerships**: Links with organizations and stakeholders to develop new/expanded data sources
- **New/Alternative Data Sources**: Development of new data sources to provide more information, especially at the state and local levels
- **Programs, Policies, and Practices**: Activities aimed at meeting the objectives
- **Reporting**: The primary analysis of progress toward the objectives
- **Summary Measures**: The measures assessing progress in health and well-being for the United States as a whole
APPENDIX B. CONSIDERATIONS AND SUGGESTIONS FOR CREATING A DATA PARTNERSHIP INFRASTRUCTURE AND NETWORK

a. Refine the Network Concept: Convene a Partnership Network Development Group
A suggested first step in implementing the Data Partnership Network is to learn from others who have created successful, large-scale, federated networks of data using shared common data models (e.g., Health Care Systems Research Network’s [HCSRN] Virtual Data Warehouse [VDW], PCORnet®, National Cancer Institute-funded datasets in cancer, surveillance).

A parallel step would be to bring together entities that could contribute to national, tribal, state, territorial, and local efforts and progress to meet a subset of objectives (e.g., the Leading Health Indicators, or LHIs). Such groups can inform one another. A benefit of using the LHIs is that they would optimize the value of content and data to Healthy People.

The gathering of network representatives would include selected Healthy People users, including those who are responsible for implementing Healthy People and those whose resources could be important to the initiative. Participants should come to the table with an awareness of data and information issues. They would be asked to comment on issues such as the merit of the Data Partnership Infrastructure concept, proposed roles for partners in the network, support required to launch and maintain the network, and outcome measures for success.

b. Suggested Groupings of Data Partnership Network Members
One “input” to the meeting would be an outline of the Committee’s data recommendations. Ethics and privacy issues should be kept front and center, and an ethicist should be invited to attend the gathering to represent these issues. Organizations relevant to the upstream determinants of health, such as the Department of Housing and Urban Development (HUD) or the Department of Justice, should also be invited. Social media groups should be invited if the Data Partnership Network is considering mining social media data. Other key stakeholders representing a wide variety of interests and expertise should also be considered.

Examples of entities that could serve as members of the Data Partnership Network:

Government or government related
- Centers for Disease Control and Prevention (CDC)
- HHS Data Council (city, state)
- National Center for Health Statistics (NCHS)
- National Committee on Vital Health Statistics (NCVHS)
- Patient-Centered Outcomes Research Institute (PCORI)
● San Diego County Health Department as well as other state and county health departments

**Research and development and data dissemination organizations**

- 100 Million Healthier Lives
- AcademyHealth
- America’s Health Rankings
- Association of Schools of Public Health
- City Health Dashboard
- County Health Rankings
- Digital Bridge
- Electronic Health Records Developers
- Foundations including Robert Wood Johnson (RWJ), Kresge, Arnold, MacArthur, de Beaumont, etc.
- Google/Verily
- Health Care Systems Research Network (HCSRN)
- Health schools (e.g., public health, medical, nursing), business schools, data science
- Health Enhancement Research Organization (HERO)
- IBM Watson
- Leading researchers
- National Interoperability Collaborative
- Qualified entities who get data from the Centers for Medicare and Medicaid Services (CMS) (e.g., Clarify Health)
- Data scientists who focus on data analysis and visualization
- Survey research organizations
- WIN measurement framework

c. **Key Criteria and Operating Principles to Consider in Developing a Data Partnership Network**

The following discussion points are meant to inform discussions of the Data Subcommittee and the full Committee about the structure of the Data Partnership Network.

**BROAD GOVERNANCE DECISIONS**

- Data ownership, governance, and reporting
- Resources and sustainability
- Scope and magnitude of measures
- Feasibility of launching such entities
- Engagement of an expanded range of stakeholders
PURPOSE OF THE DATA PARTNERSHIP NETWORK
- Support high-quality data collection and analyses and timely reporting from the tribal, state, territorial, and local levels and communication to the national level.
- Contribute to the national data needs.
- Support local implementation efforts through relevant data.
- Set standards (such as standard worksheets) to support these functions.
- Identify priority topics for data linkages that cross sectors.
- Develop and test new data sources, analytic methods, and reports as needed.

ELIGIBILITY CRITERIA TO BECOME A DATA PARTNERSHIP NETWORK MEMBER
- Demonstrated skills and abilities: experience with or capacity for surveys, programs, and/or data methods and data quality
- Exhibit dedicated focus on Healthy People initiatives
- Be accessible to a range of data users
- Have a plan for maintaining the development and operation of the network over the 2020–30 decade

SUSTAINABILITY PLAN
- A plan should be developed to ensure continued operation of the network over the 2020–30 decade.

ORGANIZATIONAL STRUCTURE OPTIONS FOR THE DATA PARTNERSHIP NETWORK
- Federal partnerships or “national data” partnerships?
- Freestanding, hybrid, or extensions of federal activities or organizations (for example, NCHS)?
- Public, private, nonprofit, or a mix?
- Could a National Data Partnership focus on a defined topic or a set of topics, or could it cover a given scope of measures across multiple topics?
- Should collaborations be an integral part of the network (e.g., an Association of State and Territorial Health Officials [ASTHO]/National Association of County and City Health Officials [NACCHO]/NCHS collaboration), as well as new partners such as Apple, Microsoft, EPIC, or others?

CONSIDERATIONS FOR LAUNCHING AND TESTING THE FEASIBILITY OF A DATA PARTNERSHIP NETWORK
- Begin development of the network by selecting 1 or 2 high-priority use cases to explore alternative structures for a collaborative network (for example, a focus on objectives and data related to the opioid epidemic). Other Healthy People 2030 objectives and associated data can then be added to grow the network based on experience and subsequent evaluation.
- Develop a “blueprint” that would include criteria for approving partner organizations.
● Entities that meet these criteria could receive “Healthy People Data Infrastructure Partner” certification, providing the entity with Healthy People branding (i.e., a stamp of approval). The creation of such entities could enable NCHS to provide technical assistance, oversight, and support for maintaining the partner “brand” and contributions. This would expand the leadership reach and support that NCHS can provide.

d. Examples of Data-Related Partnerships

These examples are included to inform discussion and further define the concept of a Data Partnership Network and ensure a “line of sight” between the National Data Partnerships and Healthy People 2030 objectives and associated metrics.

● NCHS model partnerships:
  ○ National Death Index: States own the data, and NCHS contracts with states for specifics (plans for similar model for birth data)
  ○ Interagency Agreement between HUD and NCHS
  ○ Linkage between NCHS and Social Security data
  ○ USALEEP project: Neighborhood Life Expectancy Project (Obtain input from Paul Sutton, Department of Veterans Services, https://www.cdc.gov/nchs/nvss/usaleep/usaleep.html)
    • Consider potential for using and building upon these centers.
    • Question: Can the centers be used to catalyze communities of data users and stimulate formation of National Data Partnerships?

● Partnerships between federal statistical agencies and leading research institutions

● Secure facilities that provide authorized access to restricted-use microdata for statistical purposes

● Federal partners: https://www.census.gov/about/adrm/fsrdrd/federal_partners.html

● 29 research data centers: https://www.census.gov/about/adrm/fsrdrd/locations.html

● State models: California (California Health Interview Survey [HIS])—UCLA Center for Health Policy Research and UCLA Fielding School of Public Health: http://healthpolicy.ucla.edu/chis/Pages/default.aspx


● Foodborne Diseases Active Surveillance Network (FoodNet): CDC, 10 state health departments, U.S. Food and Drug Administration (FDA), United States Department of Agriculture (USDA): https://www.cdc.gov/foodnet/about.html


● HCSRN: The VDW as the example of a shared common data model among health systems across the nation (http://www.hcsrn.org/en/Tools%20&%20Materials/VDW/)

● North American Association of Central Cancer Registries (NAACCR): An example of data collected, housed, and owned at the local (state) level according to required national
specifications, and then shared with NAACCR for national use and research projects. NAACCR does provide certification to local cancer registries if they meet certain benchmarks (https://www.naaccr.org/).

e. Additional Examples Focused on Data Entities, Health Data Organization, and Applications That Are Similar to Healthy People

Examples of State Open-Data Portals

- New York: https://data.ny.gov/
- California: https://data.ca.gov/
- Minnesota: http://www.state.mn.us/opendata/

Professional Organizations

- ASTHO: Guides to State Health Improvement Plans and their data sources
- NACCHO

Examples of Local Integrated Data and Policy Initiatives (Highlighted in Implementation Subcommittee)

- Public Health Alliance of Southern California: https://phasocal.org/
- Community Dashboard Reports: