

ATTACHMENT I – PROJECT TOPIC

National Center for Health Statistics: National Vital Statistics System Modernization— New Opportunities for Interoperable Data

Key Objective

The objective of this project is to highlight new opportunities for the use of interoperable health data to support timely research and public health surveillance. For the purposes of this project, “data interoperability” encompasses a wide range of related topics—data quality, standards, metadata, definitions, systems, and technologies—needed to share information effectively and to support the creation of better evidence for decision-making.

The results of this project will inform planning for both the National Vital Statistics System (NVSS) and a potential future National Secure Data Service (NSDS) by highlighting the possible applications for interoperable data, the level of data access needed for these uses, and the related privacy and confidentiality implications. Furthermore, insights from recent NVSS efforts to modernize health data interoperability can inform best practices for an NSDS and the broader data and evidence ecosystem.

Key Evidence Building Considerations

The COVID-19 pandemic spotlighted the need for more timely, accurate, and reliable statistics. Researchers, program administrators, and policymakers continue to look for ways to connect Federal government data to other sources of information to yield better evidence for decision-making. Information collected and held by state, territorial, local, and tribal governments hold much promise for filling data gaps. A lack of interoperability, however, often inhibits data access, analysis, and action.

The Advisory Committee on Data for Evidence Building envisioned an NSDS as a new entity supporting cross-cutting activities throughout the data and evidence ecosystem. To do this successfully, an NSDS must explore ways to systematically foster data interoperability. Recent NVSS modernization efforts demonstrate the benefits of data interoperability, present new evidence-building opportunities, and provide insights for metadata infrastructure that stretch far beyond the health domain.

NVSS is the oldest and most successful example of intergovernmental data sharing in the public health realm. It is the mechanism by which the National Center for Health Statistics (NCHS) collects and disseminates critical information on births and deaths. The NVSS comprises a multitude of systems that carries about 6.5 million records a year from the local level through states to the national level, and back again.

Over the last decade, NCHS has been collaborating with its jurisdictional partners—that is, the 50 states, 2 cities (Washington, D.C. and New York City), and 5 territories (Puerto Rico, the Virgin Islands, Guam, American Samoa, and the Commonwealth of the Northern Mariana Islands)—to improve the receipt, coding, review, analysis, and release of vital statistics. More recently, the CARES Act provided funding to

all 57 jurisdictional partners to enhance data quality and timeliness, including working toward the use of common standards and accelerating data transfers.

For example, the electronic exchange of mortality data between NCHS and vital records jurisdictions now relies on the Fast Healthcare Interoperability Resources (FHIR) standard. Using this standard improves interoperability by allowing data to be used by multiple parties for multiple purposes. A key benefit is that it enables linkages across vital records and with other datasets, providing better evidence for decision-making by both federal agencies and their state and local partners.

The American public is reaping the benefits of these investments. For example, in April 2020, NCHS began publishing provisional death counts weekly with geographic and demographic details. This information was critical to shaping the pandemic response at the national, state, and local levels. NCHS will continue to feature these numbers as a tool for recognizing and monitoring emerging health threats.

The improved interoperability of the nation's vital statistics is opening new doors for more real-time analysis and decision-making at all levels of government. This project seeks to utilize America's DataHub Consortium (ADC) to identify untapped opportunities for leveraging NVSS data and to inform data interoperability standards more broadly, including highlighting best practices for a potential future NSDS.

Project Highlights

The ADC member awarded this project would perform an in-depth environmental scan beyond the NVSS and deliver a report that addresses the following topics:

- What are the most promising uses for interoperable vital statistics to support timely research and public health surveillance? What are the key criteria for this determination? How do unmet needs vary across the Federal, state, and local levels?
- What would be the minimal level of data access (e.g., aggregated data or confidential microdata) to meet the needs identified by these opportunities?
- What are the current and foreseeable risks to privacy and confidentiality in meeting these needs? How could those risks be mitigated while maximizing the utility of interoperable health data for better decision-making?
- How could this project inform the functions and services of an NSDS, including highlighting metadata infrastructure requirements? What are the minimal and ideal metadata required for interoperability? What are best practices for establishing consistent standards across metadata types, datasets, and documentation?