Data Modernization Workshop: Building on Shared Services and Enterprise Technologies

May 19, 2021 – May 21, 2021

Welcome Remarks

Keynote Session | May 19th

Moderator
Charlie Ishikawa, Kahuina Consulting, LLC

Presenter
Dan Jernigan, Center for Disease Control and Prevention
Introductions

Dan Jernigan, MD, MPH
Acting Deputy Director for Public Health Science and Surveillance
Centers for Disease Control and Prevention
What's Next for Data Modernization?

Daniel B. Jernigan, MD, MPH
Acting CDC Deputy Director for Public Health Science and Surveillance

May 19, 2021
WE NEED TO TALK ABOUT DATA MODERNIZATION.

Conference Panel Summaries

Emerging Laboratory-Based Reporting: Opportunities and Challenges for Surveillance

Daniel B. Jerjen
Centers for Disease Control and Prevention, Atlanta, Georgia, USA

Public health surveillance has been defined as the ongoing systematic collection, analysis, interpretation, and feedback of health data. In the past, laboratory surveillance reports were critical to public health surveillance because they facilitated the investigation of mass outbreaks of epidemics diseases or outbreaks of infections. The current system of laboratory reporting, which relies on paper reports delivered by mail, is slow and susceptible. Electronic laboratory-based reporting (ELR) is likely to be more timely and complete. A number of challenges must be addressed before ELR can be scaled effectively, as technical barriers are encouraging, and costs of implementation have resulted.

ELR Challenges

The laboratory landscape is changing. Large national and regional laboratories have developed advanced information technology (IT) capabilities and use standardized test codes, enabling ELR possible. However, many smaller laboratories do not use IT, while many larger laboratories lack the necessary IT infrastructure to transfer data from the laboratory to the agency. Both large and small laboratories have reporting regulations that are not standardized for electronic reporting, and health department staff often have limited knowledge of electronic data interchange technology. In the past, public health agencies have focused more on epidemiology and statistics, and less on IT.

ELR Activities

The Centers for Disease Control and Prevention (CDC) and the National Institute of Allergy and Infectious Diseases (NIAID) have been working to develop electronic collaborative reporting between the laboratory and the agency. The goal is to improve the flow of data by standardizing test codes, data reporting formats, and transmission standards. The Centers for Disease Control and Prevention (CDC) and the National Institute of Allergy and Infectious Diseases (NIAID) have been working to develop electronic collaborative reporting between the laboratory and the agency. The goal is to improve the flow of data by standardizing test codes, data reporting formats, and transmission standards.

References

WHAT IS THE DATA MODERNIZATION INITIATIVE?

A national effort to create modern, integrated, and real-time public health data and surveillance that can protect us from any health threat.
The World of Disease Is Changing

Protecting Americans from the Public Health Crisis of Our Time

Sexually Transmitted to Record High, C.D.C.

Cases of syphilis, gonorrhea and chlamydia in the United States jumped last year, and an alarm was raised last week about congenital syphilis.

Vaping Illnesses Climb Upward, Nearing 1,300 With 29 Deaths

The U.S. death toll from vaping illnesses has topped 272,000, as CDC pushes ahead with plans for expected vaccine rollout.

Still unexplained, the illness, still under investigation, is now nearing 1,300 cases and 29 deaths, with signs that it may be controllable.

Polio-Like Cases in Children Alarms Doctors

Cases of a mysterious paralysis, known as acute flaccid myelitis, or AFM, have spiked every two years since 2014.
The World of Data Is Changing

- In a world of proliferating data that can affect public health, the right data in the right form with the right person is essential.

- An enterprise view of the “world of data” can offer insights that make information more timely, accessible, content rich, and cost effective.
DMI Is a Unifying Foundation for Change

DMI IS BOTH RESOURCED AND COMPREHENSIVE, AND IT UNIFIES US IN WAYS NO OTHER STRATEGY HAS BEFORE.

PARTNERSHIP

- Unprecedented connection to public health and healthcare partners, state and local health departments, researchers, academics, innovators, and industry leaders

CONGRESSIONAL SUPPORT

- First-ever funding dedicated to modernization, accelerated by CARES

PUBLIC SUPPORT

- New threats change awareness and demands

CDC SUPPORT

- Unified, whole-of-agency approaches
The Public Health Ecosystem
COORDINATED AND SEAMLESS EXCHANGE OF DATA

Reduce Burden + Add Value

Enhance + Promote Interoperability

Put Data to Action

DATA PROVIDERS

CORE STLT-BASED

Other

Immunization Information
Birth + Death Registration
Syndromic Surveillance
Integrated Case-Based Surveillance

CDC-OPERATED

EIP
NSSP
DCIPHER
NNDSS
IMZ Gateway
NVSS
NBS
NHSN

IMPACT

Inform the Public
Evaluate Health Outcomes
Drive Decision Making

New + Alternative Data Sources
Labs
Healthcare Providers
WE ARE GROWING FROM A STRONG FOUNDATION.
Gives faster understanding of emerging health threats through electronic reporting of emergency department visits

Reduces burden on states for reporting notifiable diseases to CDC through modernized electronic messages

Offers earlier disease detection and intervention through automated reporting of certain diseases and conditions from electronic health records

Supports faster, more complete automated laboratory reporting of notifiable conditions to local and state health departments

Captures data from ~6 million births and deaths annually that can signal changes in trends, monitor urgent public health events, and provide faster notification of cause of death
The American Rescue Plan (ARP) Act provided an additional $500 million to CDC to advance surveillance and analytics infrastructure, as well as establish a forecasting center for emerging biological threats.

FY 2020 appropriation provided CDC with $50 million to modernize its IT and data systems.

FY 2021 appropriation provided CDC with $50 million to continue data modernization activities.

The Coronavirus Aid, Relief, and Economic Security (CARES) Act provided an additional $500 million to CDC to advance surveillance goals for the nation.
Road Map

CDC Roadmap of Activities + Expected Outcomes for DMI:

- Lays out a path from where we are now to where we need to be
- Presents a vision
- Guides resources
- Tracks progress
Create interoperable system: federal, state, local and healthcare
Coordinate investments, decisions, and policies across CDC and partners
Make data sharing easier through common policies, practices and standards
Advance academic and private partnerships

If we (CDC and partners) do this …

If we (CDC and partners) do this …

ACTIVITIES

COORDINATE
PEOPLE +
SYSTEMS

Accelerate
DATA FOR
ACTION

Support
STRATEGIC
INNOVATION

- Identify data for priority public health needs
- Upgrade and modernize IT infrastructure
- Strengthen the data science workforce
- Accept open standards and tools while protecting data security
- Translate data into evidence-based recommendations

- Create interoperable system: federal, state, local and healthcare
- Coordinate investments, decisions, and policies across CDC and partners
- Make data sharing easier through common policies, practices and standards
### SHORT-TERM OUTCOMES

**COORDINATE PEOPLE + SYSTEMS**
- **Increased** collaboration, communication, and messaging among CDC and partners
- **Reduced** data collection and reporting burden at state, tribal, local, and territorial levels
- **Improved** data sharing and interoperability through common standards HL7®FHIR®
- **Increased** capacity to quickly analyze, interpret, and act on data

**ACCELERATE DATA FOR ACTION**
- **Increased** electronic reporting and specific enhancements to flagship CDC surveillance systems
- **Stronger** workforce in data science, analytics, modeling and informatics
- **Targeted** real-time communication of data and results

**SUPPORT STRATEGIC INNOVATION**
- **Integration** and use of data from new or non-traditional sources
- **Improved** pathways to explore, develop, and deploy next-generation technologies
- **Quick**, continued data analysis with adjustment of modeling in real time
**INTERMEDIATE OUTCOMES**

**COORDINATE PEOPLE + SYSTEMS**
- **Effective** coordination on complex health and emergency challenges
- **Timely** and complete data reporting to CDC
- **Efficient**, secure data access and exchange between systems across the country
- **A more comprehensive picture** to improve decision-making and protect health for all

**ACCELERATE DATA FOR ACTION**
- **Real-time**, linked systems that recognize threats early to inform timely response
- **A highly skilled workforce** that applies state-of-the-art data skills and tools
- **High-quality information** and guidance to protect people’s health

**SUPPORT STRATEGIC INNOVATION**
- **Open-source**, enterprise-level technologies and coordinated systems
- **New approaches** to address present and future threats
Long-term Outcomes

**CDC** can rapidly identify and effectively mitigate emerging threats

**Trusted data** promotes evidence-based behaviors, interventions, and solutions to protect health

**Every American** has equal opportunity to attain the highest level of health possible

**All people** have the right information at the right time to make decisions

**Our country** is better prepared for, and protected from, all types of public health threats
DATA TO STLT PARTNERS
Technical and policy solutions for timely, complete, and accurate data from EHRs, labs, and other primary data sources to STLT partners

DATA TO CDC
Streamlined, coordinated, and interoperable public health reporting via API gateways supporting timely, complete, and accurate bi-directional data flows between STLT public health partners

BUILDING A PUBLIC HEALTH WORKFORCE
Reskilling, upskilling, recruitment, and retention of a data science workforce with skills to design, implement, sustain, and innovate data modernization efforts

ONGOING DATA MODERNIZATION AND INNOVATION
Leverage state-of-the-art analytics and data visualization capabilities to integrate data from new or non-traditional sources with minimal IT assistance to strengthen the detection, response, and prevention of health threats
We cannot solve our problems with the same thinking we used when we created them.
WE NEED TO CHANGE HOW WE THINK ABOUT DATA.
Harmonizing efforts across the public health ecosystem will help us better collect, connect, track, and predict, allowing us to make more informed decisions and take more targeted action.
Foundation Activities Supporting DMI

**ENTERPRISE CLOUD SERVICES (ECS)**
- Streamlining of ATO Processes
- Enterprise Cloud Service (ECS)
- New Information Protection Technologies
- Cloud Engineering & Compute Services

**ENTERPRISE DATA ANALYTICS AND VISUALIZATION (EDAV)**
- CDC Data Academy
- EDAV Platform
- EDAV Consulting

**IDENTITY AND ACCESS MANAGEMENT**
- Integrated & Rapid Authentication Services
- ID Proofing

**RESEARCH, DEVELOPMENT AND INNOVATION (RD&I)**
- Program-OCIO Service Integration
- Data Governance and Interoperability Fabric
- Human Centered Design (HCD) and Innovation Services
An Integrated Agency Analytics Platform

Data Academy
Self-paced data science training
Providing staff with a series of learning pathways for using common data science and visualization tools.

Data Consultations
Multidisciplinary Team Of Data Experts
Dedicated team of data architects, data scientists, and public health scientists to support program data integration needs.

Programs Supported: 21
Total Projects: 32
Active Projects: 23
DW Datasets: 68
Data Lake Files: 59,108
Storage Used: 15 Tb

Data Lake
Azure Gen2 Data Lake

Data Pipelines
Azure Data Factory

Data Analytics
Enterprise R Server w/Python
Spark/DataBricks

Data Warehouse
Azure Synapse

Data Catalog
Alation

Data Visualization
Tableau Server
Power BI
R Shiny/R Connect

Public Data Catalog
Socrata
SUSTAINABLE

SECURE

TRANSPARENT

REUSABLE

EXTENDABLE

ALIGNED

ADAPTABLE

Derived from https://nam.edu/procuring-interoperability-achieving-high-quality-connected-and-person-centered-care
Select Accomplishments

Sometimes when you are asked to do the impossible, you have to do the impossible.

Dr. Anthony Fauci on getting reports on all COVID tests

- New unified IT and Data Governance saved CDC ~$11M on investments
- Expanded open data with 158 new datasets added to data.cdc.gov in 2020 – a 19% increase from 2019
- Increased capacity for states to receive and report electronic lab data, from thousands of reports per week for all conditions to millions per week just for COVID-19
- Reduced lag time on provisional death data (from months to weeks) and expanded race and ethnicity data to inform COVID-19 response
- 5.8 million COVID-19 electronic initial case reports sent to 62 health agencies as of January 27, 2021
- All 50 states, D.C., and 11 large local jurisdictions are now capable of receiving COVID-19 electronic case reports (eCR) up from only a handful of jurisdictions in late 2019
- Recent innovations have brought completeness of race information in syndromic surveillance to 93%, up from 80% in 2019

Sometimes when you are asked to do the impossible, you have to do the impossible.
Making the Impossible ... Possible

VACCINE TRACKING

COVID GENOMICS

LEVERAGING CHATBOTS
WE CAN ONLY
MOVE
FORWARD
TOGETHER.
We need to strengthen every link in the chain.
The Public Health Ecosystem
TOWARD COORDINATED AND SEAMLESS EXCHANGE OF DATA

Reduce Burden + Add Value  Enhance + Promote Interoperability  Put Data to Action

DATA PROVIDERS  CORE STLT-BASED  CDC-OPERATED  IMPACT

Data Hub for Common Ingress + Egress
Birth + Death Registration
Integrated Case-Based Surveillance
Immunization Information
Syndromic Surveillance
Other

Data Hub for Common Ingress + Egress

EIP
NSSP
DCIPHER
IMZ Gateway
NDSDD
NHSN
NBS
NVSS
NBS

Inform the Public
Evaluate Health Outcomes
Drive Decision Making

New + Alternative Data Sources
Healthcare Providers
Labs
Opportunity

Services developed and adopted by the FHIR community can help solve the “last mile” problem of getting data to multiple levels of public health.
Support to Jurisdictions

Three Tiers of ELC Funding for Jurisdictions

Tier 1. Core Data Modernization Infrastructure

Tier 2. eCR Scale Up

Tier 3. NVSS Modernization
WHAT DOES SUCCESS LOOK LIKE?
What Can We Do as Modernization Leads?
WHAT ARE THE QUESTIONS?
SKILLS SHOULD WE HAVE?
CAN WE DO TO PROTECT PEOPLE?
WHERE CAN WE INNOVATE?
OPTIONS ARE MOST COST EFFECTIVE?
CAN WE USE TECHNOLOGY?
WHO NEEDS IT?
WHY DOES IT MATTER?
BETTER DATA SAVES MORE LIVES.
Questions
Questions?

• Raise your hand
• Type your questions into the chat
• Use reactions to communicate with presenter.
Next steps

• Continue the discussion on the message board (link provided in the chat).

• Five-minute break: 12:15–12:20 PM EST

• Next session: 12:20 – 1:00 PM EST
  • Plenary: Sustainable and scalable public health infrastructure
Thank you.