

Data-Driven Decision Making Carolinas Pandemic Preparedness Task Force

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Data for Public Health Purposes

- Applied epidemiology application of epidemiology to produce outcomes or research efforts designed to address PH issues.
- Pandemic Response Goals:
 - Maintain the integrity of epidemiologic principles to use available data
 - Assure rapid response
 - Coordinate with partners to stop a pandemic due to a <u>respiratory</u> <u>virus</u>
- During COVID-19 response:
 - data was used for effective, collaborative interventions, assuring situational awareness, and educating the public
 - Pressures to stray from authorized or recommended data use adversely affected decisions, garnered misunderstanding of facts and circumstances, hindered the implementation of disease control principles.



Legal Considerations

SECTION 44-1-110. Duties of department in regard to PH, in general

- DHEC is the sole advisor of the State in all question involving the protection of PH within its limits.
- DHEC is prohibited from releasing patient-identifying information. This information must be kept confidential.

SECTION 44-1-80. Duties and powers of board as to communicable or epidemic diseases.

 Information sharing on illnesses and conditions between authorized individuals must be restricted to information necessary for the treatment, control, investigation, and prevention of PH emergencies.

Data Release and Data Sharing Agreements - Signed agreements between data owners and recipients are required. They define: justification/purpose; variables; secure means by which data will be transferred and maintained; role-based access; and assurances that the confidentiality of the data will be maintained.



Protecting Confidentiality and Providing Data for Action

SECTION 44-4-560. Access to protected health information; disclosure.

- Protected health information held by DHEC must not be disclosed to others without individual specific informed authorization with exceptions
- The Act also defined protected health information as, "any information...that relates to an individual's past, present, or future physical or mental health status, condition, treatment, service...and that reveals the identity of the individual...or where there is a reasonable basis to believe such information could be utilized to reveal the identity of that individual."
- Data Suppression prevents the release of information that alone or with other information could reasonably lead to identifying a person.



Expectations for Data In An Unfolding Pandemic

Ideally Data is:

- Systematically collected
- Representative of the population of interest
- Validated
- Data collected by must be used for public health purposes. Data is not the same as Intelligence
- For emergency response, "The ability to collect, analyze, assess and disseminate intelligence on disaster impacts is essential to support response and logistical priorities. Intelligence supports predictive analysis pre-event and shapes response actions post event."
- Data to plan for the unknown Predicting human behavior that impacts disease spread; viral mutations, competing agendas



Defining Data Types

- Reported Cases of Conditions epidemiologic data
 - Demographics
 - Risk Factors
 - Outcomes

Resource Data

- Bed capacity, ventilators, staffing
- Therapeutics
- Testing supplies
- Vaccine doses
- Vaccine Coverage Levels
- Data for Research
- Behavioral Data vital data that is lacking







Communicable Disease Data Management

- SCION The electronic communicable disease data base, and event-based management systems for reported cases and outbreaks.
- SCION Was not: a lab-results management system; used to manage negative lab results; a patient encounter system.
- Ideally reports by ELR, or provider entries into the web-based portal,
- Many that are required to report, e.g., doctor's offices, hospital systems, submit data by fax, mail or phone that must be hand entered.
- Role-based access to SCION must be approved



Understanding Data Sources for COVID-19 Response

- Lab and case reports to DHEC Population-based data
 - Electronic Laboratory Reports
 - Non-traditional reporters: LTCF, prisons, schools, work sites
- Lab results reported to people For individual decision making are results timely? How are results from varying test types interpreted?
- Data from Case Investigations Collecting valid data relied on a newly hired workforce of trained interviewers; cooperation of cases; reliable recall, forthcoming responses, etc.



Disease Control Data Management

Pre-Pandemic

- 1,758,658 lab reports; all conditions
- Data submitted from Labs, HCPs, Hosp.
- Data validation given dys-wks for case investigation and confirmations. Notifiable disease report data submitted to CDC annually.

• Staffing: Skilled SCION Data administrators with authorized access

Pandemic

- 15,452,881positive <u>and</u> negative lab reports.
- New venues now required to report: LTCFs, prisons, schools, home-testing.
- Increase in missing demographics, exposures, co-morbid conditions needed to define affected populations.
- Expectations for comprehensive quality assurance to produce valid, preliminary results **within hours** on a daily 24-hour reporting cycle.
- Staffing: Skilled SCION Data administrators with authorized access



Vendor Has Repaired Issues Causing COVID-19 Case Reporting Delays; Historical Breakdown Provided

FOR IMMEDIATE RELEASE: January 16, 2021

COLUMBIA, S.C. – The internal database used by the South Carolina Department of Health and Environmental Control (DHEC) to track COVID-19 cases experienced software problems that caused incomplete case reporting for several days. DHEC did not cause the software issue, and the vendor has fixed the problem as of this morning.

As soon as the software error was identified, DHEC added a disclaimer to its **daily case reporting webpage** to publicly notice that data was known to be incomplete.

South Carolina's Infectious Disease and Outbreak Network (SCION) used by DHEC for disease surveillance is serviced by software company Conduent, and DHEC worked closely with the vendor around the clock to repair the software problem. The database issue was caused by slowdowns and delays in how SCION was able to process COVID-19 test results that are sent to the system electronically. The majority of laboratories and facilities that report negative and positive test results to DHEC do so by submitting an electronic lab report (ELR) to SCION.



Successful Uses of Data for Decisions

- Protected vulnerable populations with limited supplies of PPE and vaccines
- Provided current, evidence-based, disease control guidance specific to numerous settings, e.g. congregate settings, homes, community settings, businesses, schools, etc.
- Provided population-based data to inform the placement of resources and services to improve access to care
- Developed and disseminated timely communications specific to multiple audiences:
 - For situational awareness
 - For behavior change
 - Disease prevention and control guidance for businesses, homes, congregate settings, schools, travel, etc.



Lessons Learned: Failure to Use Good Data for Evidence-Based Decision Making - The Evidence for Masks

NEJM Journal Watch 7-14-2020

Studies Show Importance of Face Coverings in Limiting Spread of COVID-19

By Kelly Young Edited by <u>David G. Fairchild, MD, MPH</u>

A trio of studies takes a closer look at face mask use in the U.S.

Use of cloth face masks around the country increased significantly from April — when the CDC first recommended their use to prevent the spread of SARS-CoV-2 — to May, according to an *MMWR* study.

Letters

RESEARCH LETTER

Association Between Universal Masking in a Health Care System and SARS-CoV-2 Positivity Among Health Care Workers

The coronavirus disease 2019 (COVID-19) pandemic, caused by severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), has severely affected health care workers (HCWs).¹ As a result, hos-

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Kansas implemented a mask mandate on July 3; some counties opted out*

Morbidity and Mortality Weekly Report (MMWR)

CDC

Absence of Apparent Transmission of SARS-CoV-2 from Two Stylists After Exposure at a Hair Salon with a Universal Face Covering Policy — Springfield, Missouri, May 2020

Early Release / July 14, 2020 / 69

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Lessons Learned: Failure to Use Good Data for Evidence-Based Decision Making



3/31: Public Beaches, non-essential businesses 4/1: Work or home order 4/7: Limit of groups >3 4/27: Work or home order lifted
5/4: Restaurants open for limited dine-in
5/18: Close contact services and fitness facilities open
5/22: Attractions open



Lessons Learned – Share and display data to avoid misinterpretations

- Consider contributing factors when comparing different outcomes for populations groups: risk of exposure; risk of complications; access to care; vaccination rate; missing or non-representative data.
- Inferences about events occurring at the point in time they are reported e.g. reports or outcomes may be delayed. Deaths or complications like MIS-C may occur weeks after the initial report.
- Vaccine breakthrough infections don't mean vaccines don't work.
- Adverse events reported in temporal association with the administration of vaccines don't mean they are caused by the vaccines.



Understand Data Limitations for Guiding Decisions

- Early pandemic projections using SC data:
 - Developed by groups and individuals who lacked expertise in epidemiology or infectious diseases
 - Used data when reports in SC were low.
 - Reports were not representative of the population of interest
 - The characteristics of spread for the novel SARS-CoV2 virus were poorly understood
- Visual appealing products were distributed, however flawed projections based on incorrect formulas and assumptions complicated planning discussion and confused the public
- Involve SMEs in data analyses



Lessons Learned - Avoid Flawed Assumptions About Using Data

- Using zip code-level data to determine risk of exposure and make decisions about taking protective measures.
- Risk to confidentiality from releasing small numbers at the zip code level
- Addresses or zip code-level data would not reasonably identify risk for exposure, but could create a false sense of security
 - Respiratory viruses don't follow administrative boundaries
 - The infectious period of cases could have ended by the time data was accessed.
 - Early in the pandemic testing was only recommended for those with symptoms. We estimated that for every case reported to DHEC, 6-8 cases were not.



Preparedness for Communicable Disease Emergencies

- Enhance joint exercises and planning with involved partners
- Build shared understandings of responsibilities and expertise.
- A lack of acceptance of evidence-based public health interventions will challenge our ability to conduct wellcoordinated responses.
- Manage expectations among partners about available data:
 - Define circumstances under types of data to be shared will avoid or reduce conflict.
 - Planning partners should define activities for which data is needed and how it will be used. Alternatives for data can be planned to accomplish defined goals



Preparedness for Communicable Disease Emergencies

- Plan for a workforce skilled in data entry, management, and analysis and allow adequate time to obtain valid data.
- Plan for IT infrastructure to develop and support interoperable systems and provide technical support.
- Engage a "behavioral surveillance" arm including experts in behavioral science, health education, communications and marketing to help inform our decisions and messaging.
- Communicate data limitations more effectively to the general population
- Communicate expectations and endpoints to communities to foster compliance with recommendations.



2003 SARS ABBREVIATED TIMELINE

March 12: WHO issues a global alert for a severe form of pneumonia of unknown origin in persons from China, Vietnam, and Hong Kong.

March 15: CDC issues first SARS health alert; issues interim guidelines for state and local health departments on SARS.

March 28: SARs outbreak is more widespread. CDC begins pandemic planning.

April 4: Suspected U.S. SARS cases was 115 (ultimately reduced); in 29 states.

April 5: CDC establishes outreach team to address SARS stigmatization.

April 10: CDC issued specific guidance for students exposed to SARS.

May 6: No new probable cases in U.S. in 24 <u>hrs</u>; no evidence of ongoing transmission beyond initial travelers for > 20 days. Containment in the United States has been successful.

July 5: WHO announced that the global SARS outbreak was contained.

Rapid implementation of evidence-based disease control interventions interrupted the 2003 SARS Pandemic

Using Data for Effective Public Health Measures



A Tragedy Without Collective Grief

Final CDC SARS Timeline Entry

December 31: Globally, reports of SARS from 29 countries and regions; 8,096 persons with probable SARS resulting in 774 deaths. In the U.S., eight SARS infections were laboratory confirmed; and 19 probable SARS infections.

January 20, 2022: 55 reported COVID-19 deaths in South Carolina



Flags Planted On National Mall To Honor American Covid Deaths in September 2021, when the death total was 650,000 (photo credit: Kent Nishimura)



Questions?