PROTECTING PUBLIC HEALTH: DATA, MODELS & POLICY
Natural and Political
Observations
Mentioned in a following Index,
and made upon the
Bills of Mortality.

By John Graunt,
Citizen of
London.

1662
William Farr

1870
“Medical science will advance not by vague speculations, opinions and assertions but by registering facts,...weighing and measuring, determining relations and by applying that mighty instrument of natural science-arithmetic and mathematics.”

....William Farr (1837)
• Influenza, polio & other outbreaks in early 1900s increased recognition of importance of public health data

• States began requiring reporting of some infectious diseases

• Public health surveillance data
Ongoing & systematic collection, analysis and interpretation of health outcome data

- Recognize disease outbreaks quickly
- Track spread of disease at local, state & national levels
- Identify geographic areas of concern
- Help state & local public health departments better control disease by identifying groups at risk
- Forecast future scope of outbreak
- Evaluate disease control activities
Public Health Surveillance

- National Notifiable Disease Surveillance System Collaboration CDC & CSTE (1955)
  - States voluntarily report de-identified data to CDC.
  - List of nationally reportable diseases is dynamic
    - Now ~120 infectious & non-infectious diseases
  - Authority for mandatory reporting with states
FIGURE 1. Crude death rate* for infectious diseases — United States, 1900–1996†

*Per 100,000 population per year.
“On the basis of what has happened in the last thirty years...the most likely forecast of the future of infectious diseases is that it will be very dull...outbreaks of fatal infections derived from exotic animals...will doubtless occur in the future but will presumably be safely contained.”

..... Sir MacFarland Burnet (1972)
2 Fatal Diseases Focus of Inquiry

RARE CANCER AND PNEUMONIA IN HOMOSEXUAL MEN STUDIED

ATLANTA, Aug. 28 (AP) — Two rare diseases have struck more than 100 homosexual men in the United States in recent months, killing almost half of them, and a medical study group has been formed to find out why, the national Centers for Disease Control said today.
ZIKA
HIN1 (Swine) FLU
LYME DISEASE
TB RESURGENCE
ANTHRAX
EBOLA
COVID-19
MONKEYPOX
& on & on...
COVID-19

WAS OUR PUBLIC HEALTH DATA INFRASTRUCTURE
How Does Data Flow for Public Health Reporting?

1. Patients Seek Health Care and Services
   - Hospitals & Healthcare Providers
   - Laboratories & Testing Sites

2. Entities Report Data to Public Health Agencies
   - Emergency Departments & Urgent Care Centers
   - Vaccination Sites

3. Public Health Agencies Transform Raw Data into Usable Person-Level Information
   - Vital records
   - De-identified Data for National Aggregation
   - Time & Resource Intensive Outreach
   - Case Investigation & Patient Interviews

4. Agencies Transmit Data & Case Notifications to the CDC
   - CDC Programs & Emergency Operations Center
   - Public Health Action
     - Dissemination of Guidance, Data, Tools, & Information to Policy Makers, the Healthcare Community, & the Public

Council of State & Territorial Epidemiologists, 2021
ISSUES

Correctly Match(link) records of same person
INCOMPLETE (MISSING) DATA

RACE & ETHNICITY INFORMATION in NATIONAL COVID DATA

- ELECTRONIC LABORATORY REPORTS 29%
- VACCINE DATABASE 62%
- CASE SURVEILLANCE 64%
- EMERGENCY DEPARTMENTS 77%

CDC, Council of State & Territorial Epidemiologists, 2021
Bottleneck for U.S. Coronavirus Response: The Fax Machine

Before public health officials can manage the pandemic, they must deal with a broken data system that sends incomplete results in formats they can’t easily use.
Paper stacks of Corona Virus test results, Public Health Department, Harris County, Texas
August 15, 2021

Inside America’s COVID-reporting breakdown

Crashing computers, three-week delays tracking infections, lab results delivered by snail mail: State officials detail a vast failure to identify hotspots quickly enough to prevent outbreaks.
PUBLIC DEMAND FOR TRUSTED DATA

• RELIABLE AGGREGATED DATA

• LOCAL, NATIONAL & GLOBAL

CDC?
September 2022
Winner of 2022 Lasker Award for COVID dashboard “which set a new standard for disseminating authoritative public health data in real time and cut through noise and misinformation and became the most authoritative and trusted source of information for COVID 19”
WHAT TO MEASURE?

- Numbers of deaths
- Numbers of Hospitalizations
- Number of cases positive for infection
- Number of tests
- Positivity rate
COVID-19 POSITIVITY RATE, CALIFORNIA
April-June 2020

As COVID-19 testing increases, positivity rate has decreased

40.8%
4.5%
COVID-19 POSITIVITY RATE, CALIFORNIA
April-June 2020

As COVID-19 testing increases, positivity rate has decreased

Changing patterns of who is tested
• Symptomatic
• Home antigen testing
WHAT DO THE NUMBERS MEAN?

• Counting hospitalizations
  Persons admitted & COVID discovered incidentally

• Counting Deaths
  Death from COVID or death with COVID?
RANDOMIZED CONTROLLED CLINICAL TRIALS

REAL WORLD VACCINE EFFECTIVENESS STUDIES

Need public health data beyond clinical trials
Observational

Help Answer questions that clinical trials can’t:

- Real world effectiveness?
- Is there protection against new emerging viral variants?
- Does effectiveness wane over a long time?
- What about persons under-represented in trials?
CHALLENGE:

LINK IMMUNIZATION RECORDS WITH COVID-19 DISEASE RECORDS?

OTHER COUNTRIES HAVE RELIABLE, NETWORKS OF INTERCONNECTED DATA SYSTEMS

• United Kingdom, Israel for example
• Ability to link records
• Unique identifier numbers
MODELS
EPIDEMIC FORECAST MODELS

FLAVORS

- CURVE FITTING MODELS
- MECHANISTIC MODELS
  - biological
  - transmission
  - incubation
CURVE FITTING: AIDS

“FARR’S LAW”: BELL-SHAPE CURVE

Bregman and Langmuir, JAMA, 1990
MECHANISTIC MODEL: AIDS

BACK-CALCULATION

Incubation Period

infected → AIDS
Symptomless Victims May Spread AIDS for Years

By HAROLD M. SHMECK, Jr.

The virus of acquired immune deficiency syndrome, or AIDS, may persist without causing symptoms in the infected person for more than four years and still be transmissible through blood transfusion, scientists reported yesterday.
AIDS CASES

TESTED HIV pos (without AIDS)

UNSEEN HIV INFECTIONS (INCUBATING)

TIP OF THE ICEBERG
“Projections for the U.S. indicate that the AIDS epidemic poses a major public health problem and the epidemic will greatly exceed the cases reported to CDC as of 1986”

Brookmeyer & Gail, Lancet, 1986
Op-Ed Ron Brookmeyer  April 22, 2020

Predictions about where the coronavirus pandemic is going vary widely. Can models be trusted?

• To make predictions, curve-fitting models simply extrapolate curves into the future.

• “Because of the pitfalls of extrapolation, the Institute for Health Metrics model’s prediction of nearly zero COVID-19 deaths this summer is not considered reliable and should be viewed with extreme skepticism.”

• If you are looking for longer-term clues regarding how the pandemic will play out, pay attention to transmission models, even though they have their own built-in uncertainties.

Lowell Reed, 1951
https://www.youtube.com/watch?v=7ku71YoyGcM
Transmission models

- Agent based models
  microsimulations

- Policy Implications
  e.g. lock-downs  Aleta et al, 2020

- Rely on data for inputs and validation
Transmission models

Agent based models

Rabadan, In Understanding Coronavirus, Cambridge University Press, 2020
July 23, 2022

CDC Director Rochelle Walensky

Inconsistent data inhibits the agency’s ability to observe trends in race and ethnicity, sexual behavior and vaccination. And yet again, like we were for COVID, we are again really challenged by the fact that we at the agency have no authority to receive those data.
ADVANCES IN HEALTH DATA

- Digital Health and Information Technologies
- Computing platforms
- Mobile health
- Wearable devices
- Radiological images stored and viewed digitally
- Prescriptions transmitted electronically
- Artificial Intelligence (AI) - radiology, early disease detection
- Telemedicine
- Health apps: smart watches
• Digitalizing health care delivery
• Incentives for use of electronic health record (EHR) systems
• Accelerated EHR use
• Past decade $38 billion in incentives
BUT WHAT ABOUT PUBLIC HEALTH DATA SYSTEMS?

• UNDERINVESTMENT
• NOT MODERNIZED
• FRAGMENTED
  
  - data from healthcare providers, hospitals & labs
  - more players, clinics, tests sites
  - to 3,000 local public health departments
  - to 60 state & territorial public health departments

• JUMBLE OF DATA STANDARDS, TECHNOLOGY, PHONE, EMAIL, FAX

• SILOED DATA SYSTEMS

• DATA GAPS ESPECIALLY RACE/ETHNICITY
THE WAY FORWARD

• Invest in public health—even when there is no emergency

• Improve public health data interoperability and data exchange between the players

• Standardize data elements for data exchange

• Share and link data (confidentiality)

• Stronger coordination at the national level (CDC)

• Various initiatives underway…
PARTNERSHIP

INFORMATION TECHNOLOGY EXPERTS
EPIDEMIOLOGISTS
PUBLIC HEALTH PROFESSIONALS
STATISTICIANS
PUBLIC HEALTH COMMUNICATION SPECIALISTS
PRIVATE AND PUBLIC SECTORS
LEADERS THAT BUILD TRUST
FUTURE CHALLENGES
ADDITIONAL READINGS


