National Commission to Transform Public Health Data Systems

Robert Wood Johnson Foundation

Media Scan: Public Health Data & COVID-19

The Washington Post

How CDC data problems put the US behind on the delta variant

Yasmeen Abutaleb and Lena H. Sun

08/19/21

When Pfizer representatives met with senior U.S. government health officials on July 12, they laid out why they thought booster shots would soon be necessary in the United States. Data from Israel showed the vaccine's effectiveness waned over time, especially in older and immunocompromised people.

The Washington Post

Messy, incomplete US data hobbles pandemic response

Joel Achenbach and Yasmeen Abutaleb

09/30/21

The contentious and confusing debate in recent weeks over <u>coronavirus booster shots</u> has exposed a fundamental weakness in the United States' ability to respond to a public health crisis: <u>The data</u> is a mess.

TIME

What happens When the World's Most Popular COVID 19 Dashboard Can't Get Data?

Emily Barone

09/29/21

One Monday in late February 2020, Lauren Gardner was working frantically. The website she'd been managing around the clock for the last month—which tracked cases of an emerging respiratory disease called COVID-19, and presented the spread in maps and charts—was, all of a sudden, getting inundated with visitors and kept crashing.

Government Technology

Alabama Schools Struggling Without COVID Data Collection

Savannah Tryens-Fernandes

10/04/21

The state is not reporting or tracking the quantity or location of new outbreaks in schools, nor is it contact tracing all confirmed cases, leaving schools with sparse information to make decisions.

WFAA

Who Collects COVID 19 data in Texas and where does it go?

Jay Wallis

10/15/21

When talking about COVID-19 in Texas, there are many questions people have connected to where data comes from and how it is collected. There are four main statistics gathered and released by the Texas Department of State Health Services: cases, hospitalizations, deaths and vaccinations.

Boston.com

Children's Hospital collecting data on link between COVID and deadly MIS-C in children

Julia Taliesin

09/22/21

As COVID-19 continues to spread, more children are contracting the virus and a few are ending up with a rare but serious condition. Not much is known about multisystem inflammatory syndrome in children, or MIS-C, but Boston's own Children's Hospital is working on collecting data for federal studies.

Duke Today

The Modeling Data Behind Duke's COVID response plan

Geoffrey Mock

09/28/21

Midway through the fall semester, Duke has seen zero COVID transmissions traced back to the classroom. This is a result of a COVID response plan that in several ways distinguished itself from those at other universities: Masks in the classroom, full vaccination of faculty, staff and students, and heavy surveillance testing and quick turnaround of results.

The Commonwealth Times

VCU Health takes COVID19 research on the road with mobile RV laboratories

Lindsay West

09/29/21

VCU Health recently joined the National Institutes of Health in researching COVID-19 in children ages 0-25 and their biological families, as children are increasingly experiencing long-term symptoms post-COVID-19, according to Assistant Dean of Research, Scholarship and Innovation at the VCU School of Nursing Patricia Kinser.

Axios

What we can learn from DC's breakthrough data

Chelsea Cirruzzo

09/29/21

D.C.'s publicly reported <u>data on breakthrough cases</u> offers a unique window into how the pandemic continues to impact vaccinated people, Axios' Chelsea Cirruzzo reports.

The New York Times

Bottleneck for US Coronavirus Response: The Fax Machine

Sarah Kliff and Margot Sanger Katz

07/13/20

Public health officials in Houston are struggling to keep up with one of the nation's largest coronavirus outbreaks. They are desperate to trace cases and quarantine patients before they spread the virus to others. But first, they must negotiate with the office fax machine. The machine at the Harris County Public Health department in Houston recently became overwhelmed when one laboratory sent a large batch of test results, spraying hundreds of pages all over the floor.

Bloomberg City Lab

Coronavirus Data in the US Is Terrible and Hers Why

Marie Patino

05/01/20

Every day now comes with a new set of coronavirus data: numbers for positive tests, negative tests, deaths, patients hospitalized, ventilator shortfalls and hospital beds occupied. And, more rarely, the racial and ethnic breakdown of those who have tested positive, and those who have died. These numbers enable epidemiologists, officials, journalists and the public around the world to track the evolution of Covid-19 in almost real time, making it the first "data-driven pandemic." There's a lot at stake in these numbers, and there's a major problem: The data on which we are basing decisions is imperfect and incomplete.

Health Affairs

Health Care in 2021: Five Trends to Watch

Susan DeVore

01/20/21

History gives us many reasons to doubt predictions. In 1916, Charlie Chaplin famously called the motion pictures "a fad." In 1932, Albert Einstein said that nuclear power was not possible. In 2008, Steve Ballmer predicted the iPhone would be a flop. As these cases show, smart people may see the facts, but not the environmental factors that can shift the entire landscape. This was particularly true in 2020, a year that redefined "normal" and altered our world in ways we are only beginning to understand. In this environment, the hard job of accurately predicting future trends became that much more difficult. When I look back at my own predictions last year, almost none of them played out as I thought due to the pandemic and the complete upending of the national health care agenda.

Health IT Security

Mobile Security a Barrier to Health App use, Study Shows

Sara Heath

11/06/05

Calling into question the issue of mobile security, researchers Paul Krebs, PhD, and Dustin T. Duncan, ScD, conducted a mobile health app study, concluding that those who trust their data in health apps are generally only those who use the apps. In their study "<u>Health App Use Among US Mobile Phone Users: A National Survey</u>," Krebs and Duncan found an interesting dichotomy

regarding consumer trust in mobile app security. After surveying nearly 1,604 mobile phone users, the researchers discovered that while those who use mobile apps have considerable trust in their data security, those who do not use mobile health apps cite data security as a prominent barrier to use.

Cerner

The power of data transforming health care

Akram Sami and Mohamed AlRayyes

12/09/20

In an interview with *The Arab Hospital* magazine, Akram Sami, General Manager of UAE and Kuwait, Cerner Middle East and Africa, and Dr Mohamed AlRayyes, the Senior Physician Executive, Cerner Middle East and Africa, talk about the significance of artificial intelligence adoptions and data-driven innovations in the health care industry today.

Health IT Security

Effects on Patient Distrust on Health Data Exchange Security

Kate Monica

01/04/17

In a <u>recent survey</u>, Black Book polled a national panel of over 12,000 consumers to gauge patient interaction with technology and their perception of the usefulness of these technologies. The organization found that 57 percent of respondents are skeptical of the benefits of health data exchange technologies including EHR technology and patient portals. The chief source of their hesitancy is the result of recent health data breaches and their impact on protected health information (PHI). Simply put, patients do not trust that their information is safe.

Nextgov

Survey: Nearly 1 in 4 Consumers Distrust Government COVID Data

Frank Konkel

03/19/21

While the federal government and state and local health agencies are supposed to serve as authoritative sources of coronavirus-related information, a survey released this week suggests nearly 1 in 4 Americans do not trust pandemic-related information from these officials. The survey, conducted by Ohio-based information management firm Hyland Software, polled 1,000 consumers on their trust levels of various information sources and technologies, including artificial intelligence and social media platforms.

Health IT Security

How the FTC's Health Breach Notification Rule Will Impact Health Apps

Jill McKeon

10/05/21

Customers regularly provide their heart rate, weight, height, sleep, fertility, and other sensitive medical data to health apps. But while standard healthcare providers are beholden to HIPAA, health apps are not required to comply with the same regulatory standards when it comes to health data

breaches and patient data sharing. With its new <u>policy statement</u>, the Federal Trade Commission (FTC) affirmed that health apps and connected device companies that collect health information must comply with the <u>Health Breach Notification Rule</u>.

The Washington Post

Few states are accurately tracking coronavirus vaccinations by race. Some aren't at all.

Lola Fadulu and Dan Keating

01/27/21

Most states are not publicly reporting racial data on people receiving <u>coronavirus</u> vaccines, despite disproportionate covid-19 death rates for Black and Hispanic people and rising concerns about who has access to — and is willing to take — the vaccine.

Seven weeks after the first shots were administered, just 20 states include race and ethnicity data on their vaccine dashboards, even though it is required by the federal government. And even those states have major gaps in their data, with "unknown" being the first- or second-most frequent category in almost every state.

Urban Institute

Research Methods and Data Analytics

Sonia Torres Rodriguez

01/11/21

Amid the COVID-19 pandemic that is <u>disproportionately killing Black people</u>, <u>more than 20 cities</u>, <u>at least 3 states</u>, the <u>American Public Health Association</u>, and the <u>American Medical Association</u> have declared racism a public health emergency. Public health data glaringly highlight these disparities. The maternal mortality rate is <u>three times higher for Black women than for white women</u>, a reality that could worsen <u>under COVID-19</u>. And the average life expectancy for Black people is <u>four years lower</u> than for white people, in part because of <u>medical racism</u> and <u>police targeting of Black communities</u>.

USA Today

It's not a pretty picture': Why the lack of racial data around COVID vaccines is 'massive barrier' to better distribution

Nada Hassanein

02/01/21

After her longtime friend died of COVID-19, Abigail Echo-Hawk sat in her chair crying. She wondered if her friend and mentor, a Native American like her, would be counted among the deaths – a worry that only added to her grief. "I couldn't help this thought that ran through my head: Is his story going to be present in the data? Or did we lose him even there?" she said of the tribal leader in his mid-50s. Echo-Hawk is chief research officer at the Seattle Indian Health Board and a member of the We Must Count Coalition. The group of health equity leaders calls for better health data tracking to shed light on racial disparities because people of color suffer disproportionate rates of COVID-19 cases, hospitalizations and deaths as a result of longstanding systemic inequities and racism.

The New York Times

Does COVID 19 Hit Women and Men Differently? US Isnt Keeping Track

Alisha Haridasani Gupta

04/03/20

As the novel coronavirus sweeps the world, sickening hundreds of thousands of people and killing at least 50,000 individuals to date, scientists have learned more and more about it. We know that older adults — aged 60 and above — are at greater risk of dying from it. And, based on data from China, Italy and South Korea, we also know that men seem to have higher fatality rates. But in the U.S., where ramped-up testing is churning out reams of data by the minute, there's one thing we're not monitoring: the sex breakdown. How many women are infected versus men? Are men and women equally likely to get infected? What is the fatality rate for each sex? Are symptoms exactly alike for men and women? The latest update on cases and deaths in the U.S. from the Centers for Disease Control and Prevention contained no mention of male and female patients. When asked why, a spokesperson for the C.D.C. said the agency simply does "not have that information to share at this time" and "additional investigation is needed." Even The Times's case tracker, which was made public last week and provides county-level data, has no sex breakdown because that information isn't consistently available across states and counties.

PEW

Biden Administration Should Improve Data Exchange Practices to Promote Public Helath

Ben Moscovitch and Molly Murray

03/01/21

As state health departments continue their COVID-19 vaccination efforts and work to halt the virus's spread, a lack of critical data undermines their ability to effectively accomplish either task, a reality that could prolong the pandemic.

In some cases, test results are shared using antiquated methods such as <u>faxes</u> and may not include the demographic information needed to conduct contact tracing. Likewise, the vaccine rollout has highlighted issues with <u>incomplete data</u>; the Centers for Disease Control and Prevention estimates that it lacks data on the race and ethnicity of nearly <u>half of those who</u> have been immunized. That makes it difficult to track inequities in vaccine distribution and understand when restrictions could safely be rolled back.

Cleveland.com

COVID showed the cracks in society. How can we fix them?

Cameron Fields

03/28/21

Ohio has 113 local health departments and a computer system incapable of contact tracing. But the shortcomings of the state's antiquated public health apparatus were hidden until COVID-19, when public data was scarce, and no one could pinpoint where the virus were spreading. Problems have surfaced over and over, as the coronavirus wormed itself into every facet of society this last year, revealing broken structures and unprepared organizations, inefficiencies and disparities. More than 18,000 Ohioans have died from the coronavirus, and all have suffered some hardship.