The Network
for Public Health Law

Ideas. Experience. Practical answers.

Collecting and Disseminating Public Health Data by Race and Ethnicity to Advance Health Equity:

Navigating the Legal and Non-Legal Issues

About the Network for Public Health Law

The Network provides **visionary leadership** in the use of law to promote, protect and improve health and advance health equity.

We work with local, tribal, state and federal **public health officials** and practitioners, **as well as attorneys**, policymakers, advocates and community organizations.

We provide **information, resources, consultation and training**, as well as opportunities to connect.

Moderator

Aila Hoss is an Associate Professor at Indiana University McKinney School of Law where she teaches and researches at the intersection of health law and federal Indian law. Professor Hoss practiced public health law as a staff attorney with the Centers for Disease Control and Prevention's Public Health Law Program, where she provided legal technical assistance to state, Tribal, local, and territorial governments. Her work at CDC included supporting the agency's Ebola Emergency Operations Center and serving as a faculty member for the agency's Working Effectively with Tribal Governments course. She was previously an Assistant Professor and faculty advisor at the University of Tulsa College of Law's Native American Law Center. Her scholarship has been published in notable legal and public health venues including the *Wisconsin Law Review*, *Nevada Law Journal*, *Public Health Reports*, and *Morbidity and Mortality Weekly Report*.

Panelists

Dr. Annie Fine is a medical epidemiologist, a pediatrician and a graduate of the CDC EIS fellowship. She currently serves at the Council for State and Territorial Epidemiologists (CSTE) as the Chief Science and Surveillance Officer and Senior Advisor to the Data Modernization Initiative. Dr. Fine previously worked at the New York City Department of Health and Mental Hygiene for almost 25 years where she led efforts to modernize communicable disease surveillance at the agency. She led surveillance and epidemiologic data management for infectious diseases and many large public health emergencies in New York City, including Ebola, the 2015 Legionella outbreak in the South Bronx, Zika and most recently, COVID-19, where she led the epidemiology and data unit for the emergency response until transitioning to her new position at CSTE. She also played a major role in the responses to Pandemic Influenza H1N1, West Nile in 1999, and the 2001

Panelists

Carrie Waggoner, J.D., is a deputy director with the Network's Mid-States Region. Carrie's public health legal interests include the use of data to advance health equity, public health authority issues, laws and policies supporting employees and families, and environmental public health. Prior to joining the Network, Carrie served as the Director of the Public Health Legal Division at the Michigan Department of Health and Human Services, where she led teams providing legal support on public health, privacy, data, contracts, litigation, and FOIA-related matters. Carrie is a graduate of the Michigan State University College of Law and is licensed to practice law in Michigan.

Stephen Murphy, J.D., joined the Network for Public Health Law as a senior attorney focusing on public health data access and data sharing. Prior to coming to the Network, Stephen was an attorney for the Chicago Department of Public Health (CDPH) concentrating on public health data privacy and public health law. Stephen has a law degree from Loyola University Chicago School of Law and a bachelor's degree in economics and Spanish from University College Dublin, Ireland. Following law school, Stephen completed a judicial clerkship at the Circuit Court of Illinois, Cook County Circuit. He is licensed to practice law in California and Illinois.

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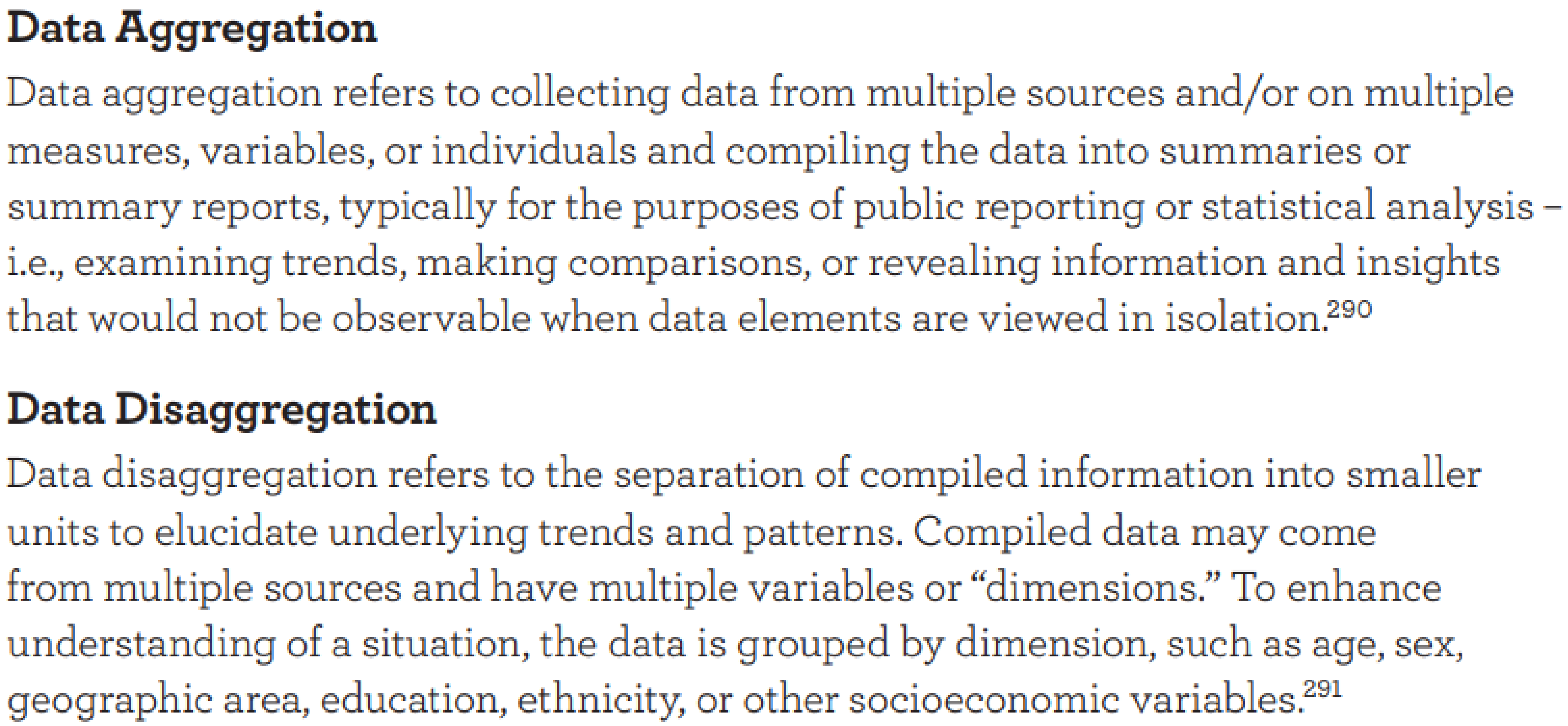
Disaggregation of Public Health Data by Race & Ethnicity

A Legal Handbook

Q: What is data disaggregation and why it is important to public health?

Key Definitions



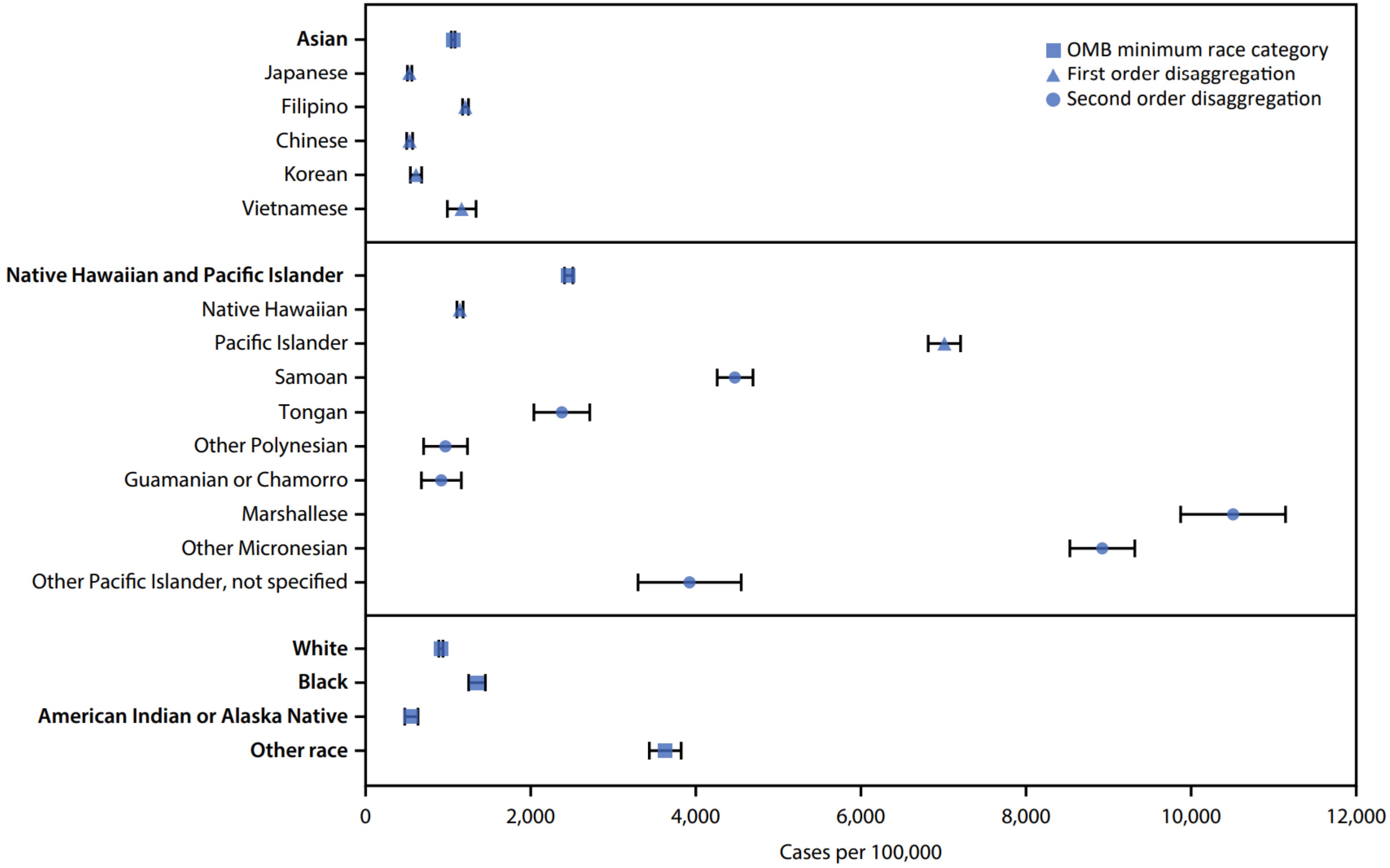
Data Aggregation

Data aggregation refers to collecting data from multiple sources and/or on multiple measures, variables, or individuals and compiling the data into summaries or summary reports, typically for the purposes of public reporting or statistical analysis – i.e., examining trends, making comparisons, or revealing information and insights that would not be observable when data elements are viewed in isolation.[290]

Data Disaggregation

Data disaggregation refers to the separation of compiled information into smaller units to elucidate underlying trends and patterns. Compiled data may come from multiple sources and have multiple variables or "dimensions." To enhance understanding of a situation, the data is grouped by dimension, such as age, sex, geographic area, education, ethnicity, or other socioeconomic variables.[291]

FIGURE. COVID-19 case rates,* by race (alone or in combination with one or more other races)†,§,¶ — Hawaii, March 1, 2020–February 28, 2021

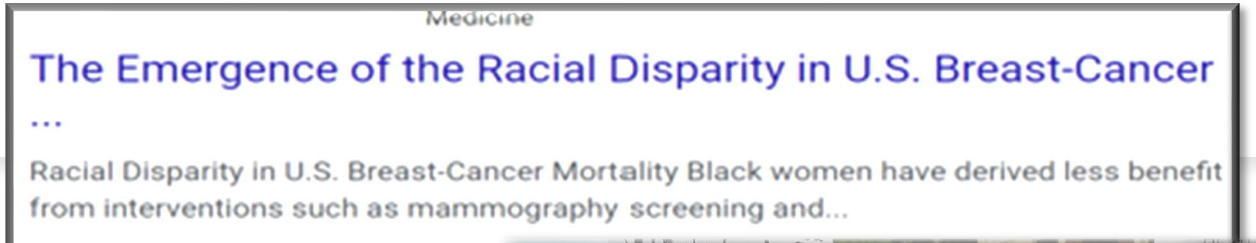


Source: MMWR 2021, https://www.cdc.gov/mmwr/volumes/70/wr/pdfs/mm7037a1-H.pdf.

Published: May 25, 2022

Asian American, Native Hawaiian and Pacific Islander adults less likely to receive mental health services despite growing need

By Laura Williamson, American Heart Association News



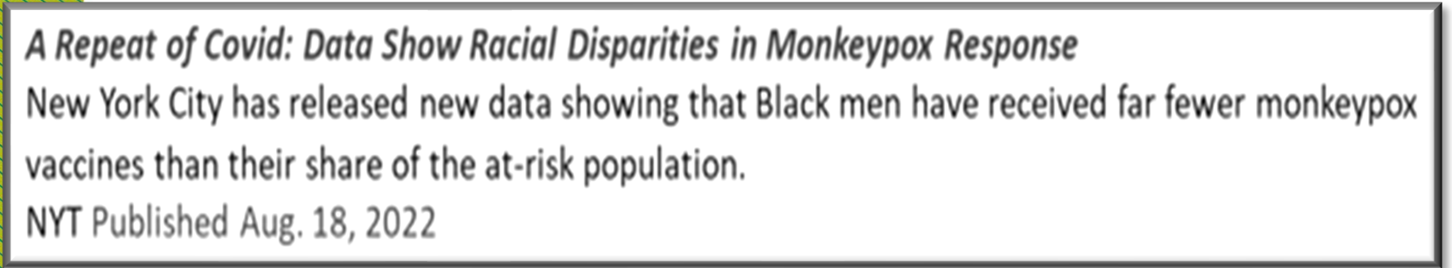
Medicine

The Emergence of the Racial Disparity in U.S. Breast-Cancer ...

Racial Disparity in U.S. Breast-Cancer Mortality Black women have derived less benefit from interventions such as mammography screening and...

Jun 23, 2022

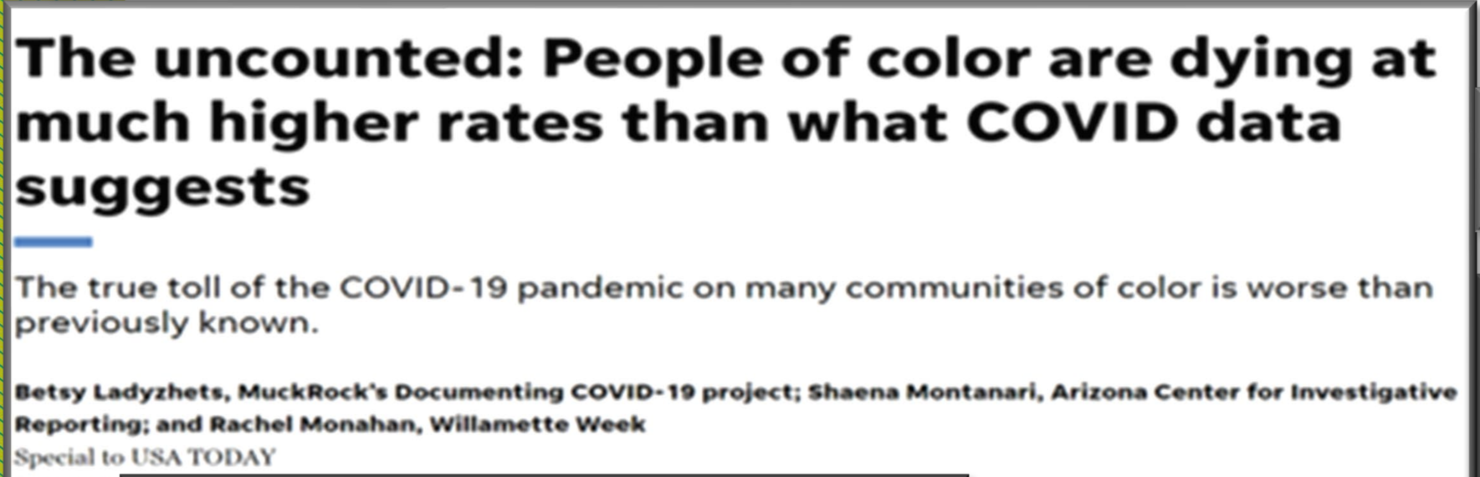
𝕿 | Published 2021



A Repeat of Covid: Data Show Racial Disparities in Monkeypox Response

New York City has released new data showing that Black men have received far fewer monkeypox vaccines than their share of the at-risk population.

NYT Published Aug. 18, 2022



The uncounted: People of color are dying at much higher rates than what COVID data suggests

The true toll of the COVID-19 pandemic on many communities of color is worse than previously known.

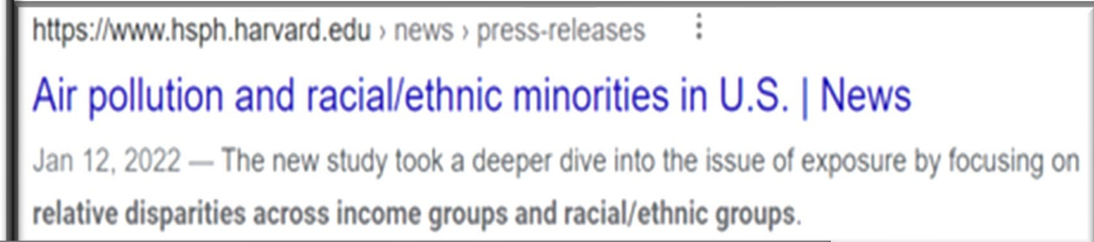
Betsy Ladyzhets, MuckRock's Documenting COVID-19 project; Shaena Montanari, Arizona Center for Investigative Reporting; and Rachel Monahan, Willamette Week

Special to USA TODAY

Published

Data lacking on missing and murdered Native Hawaiian women

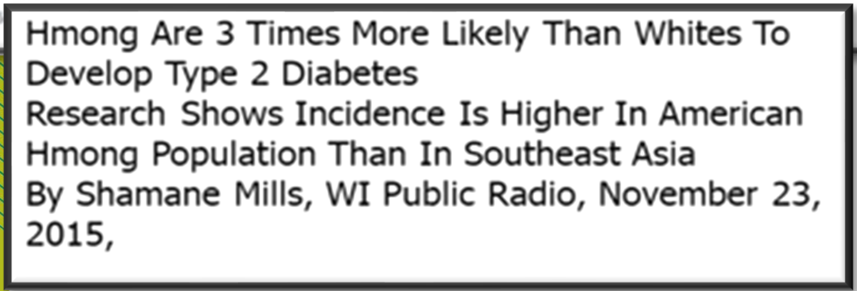
By Associated Press | Thursday, December 15, 2022, 7:05 a.m.



https://www.hsph.harvard.edu › news › press-releases

Air pollution and racial/ethnic minorities in U.S. | News

Jan 12, 2022 — The new study took a deeper dive into the issue of exposure by focusing on relative disparities across income groups and racial/ethnic groups.



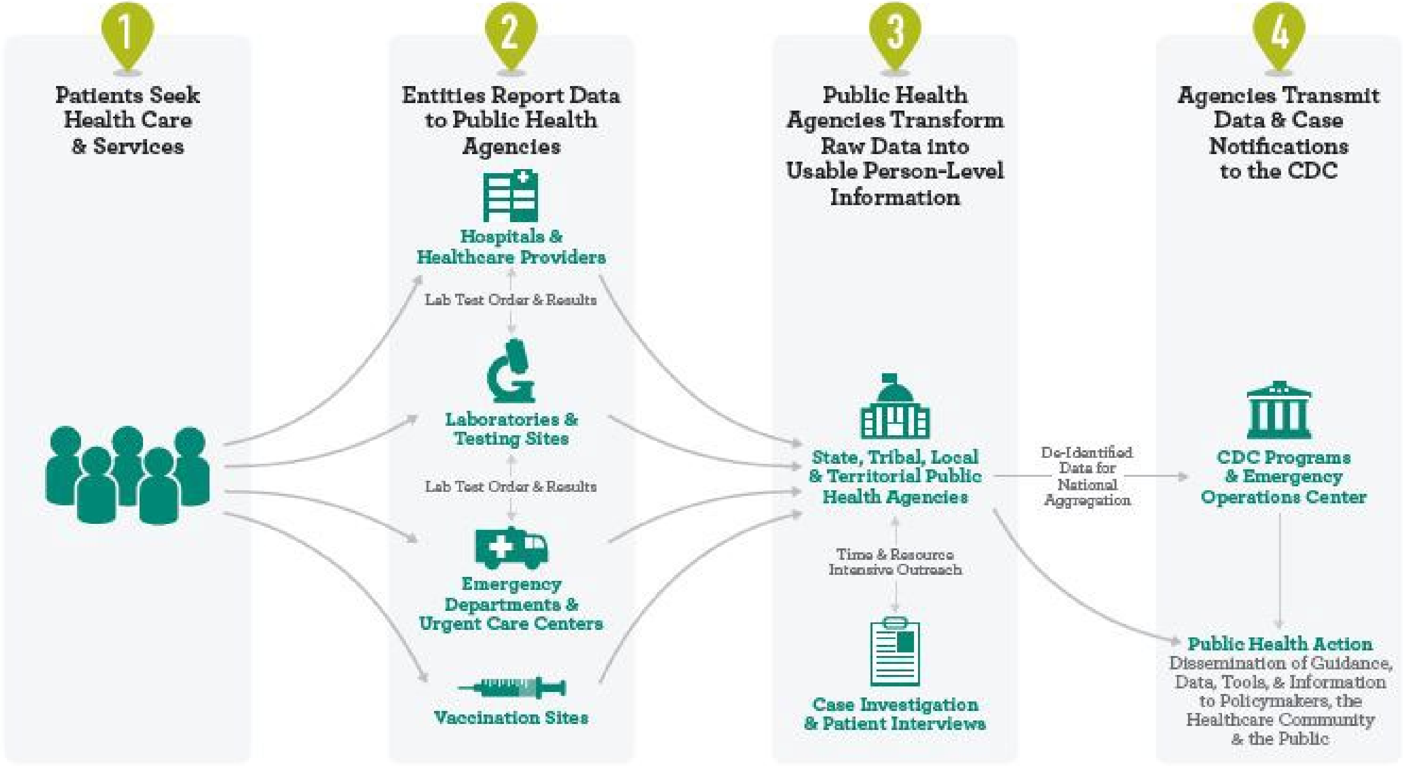
Hmong Are 3 Times More Likely Than Whites To Develop Type 2 Diabetes
Research Shows Incidence Is Higher In American Hmong Population Than In Southeast Asia
By Shamane Mills, WI Public Radio, November 23, 2015,

U.S. Department of Health and Human Services
Office of Inspector General
Data Brief
June 2022, OEI-02-21-00100

Inaccuracies in Medicare's Race and Ethnicity Data Hinder the Ability To Assess Health Disparities

Q: Can you help us understand the flow of public health data and the barriers to the collection of race and ethnicity data?

Data Flow from Healthcare to Public Health



1 Patients Seek Health Care & Services

2 Entities Report Data to Public Health Agencies

- Hospitals & Healthcare Providers
- Lab Test Order & Results
- Laboratories & Testing Sites
- Lab Test Order & Results
- Emergency Departments & Urgent Care Centers
- Vaccination Sites

3 Public Health Agencies Transform Raw Data into Usable Person-Level Information

- State, Tribal, Local & Territorial Public Health Agencies
- Time & Resource Intensive Outreach
- Case Investigation & Patient Interviews

De-Identified Data for National Aggregation

4 Agencies Transmit Data & Case Notifications to the CDC

- CDC Programs & Emergency Operations Center
- Public Health Action: Dissemination of Guidance, Data, Tools, & Information to Policymakers, the Healthcare Community & the Public

Data flow graphic provided courtesy of the Council of State and Territorial Epidemiologists & Panzer Creative, 2022.

How does PH collect and use RE data?

- Identify, measure, and report disparities in incidence and burden of disease
- Target resources/response accordingly – e.g. deliver vaccinations, ensure access to testing and preventive care, community engagement
- Many domains
- Collection and exchange of RE governed by STLT law/regulation
- Rely primarily on health care to collect race and ethnicity
- Data sources – electronic reports from health care (lab and case reports), medical record reviews, population surveys, administrative datasets, and case investigations including interviews (1:1)
- Data generally move from health care to STLT PHAs then to CDC

Q: We hear a lot about OMB race and ethnicity categories in the context of data disaggregation. What do they refer to?

TABLE 1: OMB DIRECTIVE NO. 15 CATEGORIES OF RACE

American Indian or Alaska Native
Asian
Black or African American
Native Hawaiian or Other Pacific Islander
White

TABLE 2: OMB DIRECTIVE NO. 15 CATEGORIES OF ETHNICITY

Hispanic or Latino
Not Hispanic or Latino

Q: Are the OMB categories the only categories that may be used in the collection of race and ethnicity data?

TABLE 3: ETHNICITY CATEGORIES REQUIRED FOR ALL HHS-SPONSORED HEALTH SURVEYS

No, not Hispanic or Latino/a, or Spanish origin
Yes, Mexican, Mexican American, Chicano/a
Yes, Puerto Rican
Yes, Cuban
Yes, another Hispanic, Latino/a or Spanish origin

TABLE 4: RACIAL CATEGORIES REQUIRED FOR ALL HHS-SPONSORED HEALTH SURVEY

American Indian or Alaska Native	Asian Indian
Chinese	Filipino
Japanese	Korean
Vietnamese	Other Asian
Black or African American	Native Hawaiian
Guamanian or Chamarro	Samoan
Other Pacific Islander	White

Q: What are the complexities of data classification for Indigenous communities?

Q: Disaggregation of data, as we will discuss more later on, raises privacy concerns. Help us to understand the general privacy landscape in which today's health department finds itself.

Privacy Landscape

- Web of privacy law on federal and state level
- Different confidentiality provisions apply to different public health datasets
- No state prohibits dissemination of de-identified data from reported diseases
- Standards for determining whether data is sufficiently anonymized vary

Q: Is the law a barrier or a facilitator of collection of race and ethnicity in public health data sets?

A: One of our key findings is that, in general, the law is not a barrier to the collection of race and ethnicity data in public health.

Q: What is the legal authority for public health data collection, including race and ethnicity data?

Legal Authority for Public Health Data Collection

- State and local health departments primarily responsible
- Health care providers duty to report
- Federal government supports and collects data
- OMB’s race and ethnicity categories
    - Directive No. 15
    - Baseline standard

FIGURE 3: UNDERSTANDING STATUTES, RULES, & POLICIES

	Statute*	Rule**	Policy
Who	Adopted by a legislative body (state legislature or U.S. Congress) and signed by the executive (governor or president)	Adopted by a state or federal agency acting within the bounds of its statutory authority after notice to the public and opportunity for public comment	Adopted by a state or federal agency, consistent with law or rule, without the requirement for public notice and comment
Effect	Legally binding	Often fills in details of legislation; legally binding once adopted	Explains an agency's interpretation of their rule or policy. May or may not bind the agency or regulated individuals; depends on the substance of the policy, the authority in which it is issued, and the jurisdiction

* Also known as law, Act, enacted legislation, legislation

** Also known as regulation

Q: We often hear concerns that HIPAA does not allow disclosure of protected health information (PHI) to health departments? Is this accurate?

HIPAA is not a legal barrier to public health data collection

- Public health exception to HIPAA's written authorization requirement – *see* 45 CFR 164.512(b)

Q: Does ONC's information blocking rule impact public health data collection?

A: Failure to electronically report data to health departments as authorized by law may be impermissible information blocking.

Q: Are there examples of states that have made advances in the collection of race and ethnicity data?

A: Yes.

- Oregon REALD law (Enrolled HB 2134 of 2013)
- Washington State Department of Health, Regulation 246-101-0011 (2022)

Q: Are there opportunities to use law and policy to address the non-legal barriers to data collection?

Recommendations to Improve Collection of Race and Ethnicity Data
- State level

- Utilizing existing legal authority, states should collect more race and ethnicity data across all programs
- States can explore whether to explicitly mandate reporting of race and ethnicity data
    - Oregon REALD law (Enrolled HB 2134 of 2013)
- States can explore whether to adopt penalty structures for failure to report data
    - Fines
    - Professional licensure

Recommendations to Improve Collection of Race and Ethnicity Data
- Federal level

- Federal government can do more to mandate provider data reporting and to tie financial incentives to it
- OMB should consider expanding its race and ethnicity categories
- Congress should consider codifying ongoing requirements and funding commitments to develop and maintain modern, interoperable public health data systems at all levels

Q: How do the laws related to data collection differ in the context of Tribes?

Q: The handbook describes public dissemination of disaggregated data as the crossroads of transparency and privacy. What do we mean by that?

Dissemination: Crossroads of Transparency and Privacy

Public's right and ability to access public data

- Open Data Laws
- FOIA Laws
- De-identification Standards

Protecting individual's right to privacy

- De-identification Standards
- Risks of Re-Identification

Q: What are open data laws and how do they impact dissemination of data?

Open Data Law and Policy

- 2013 Executive Order, by President Obama
    - open and machine readable to new default for government information
- Governments on all levels increasingly establishing open data portals
    - 48 states
    - 48 U.S. cities and counties
    - 53 countries
    - 165 international regions

Source: Data.gov

- 16 states have laws that mandate data be made available in open data formats
- https://www.ncsl.org/research/telecommunications-and-information-technology/state-open-data-laws-

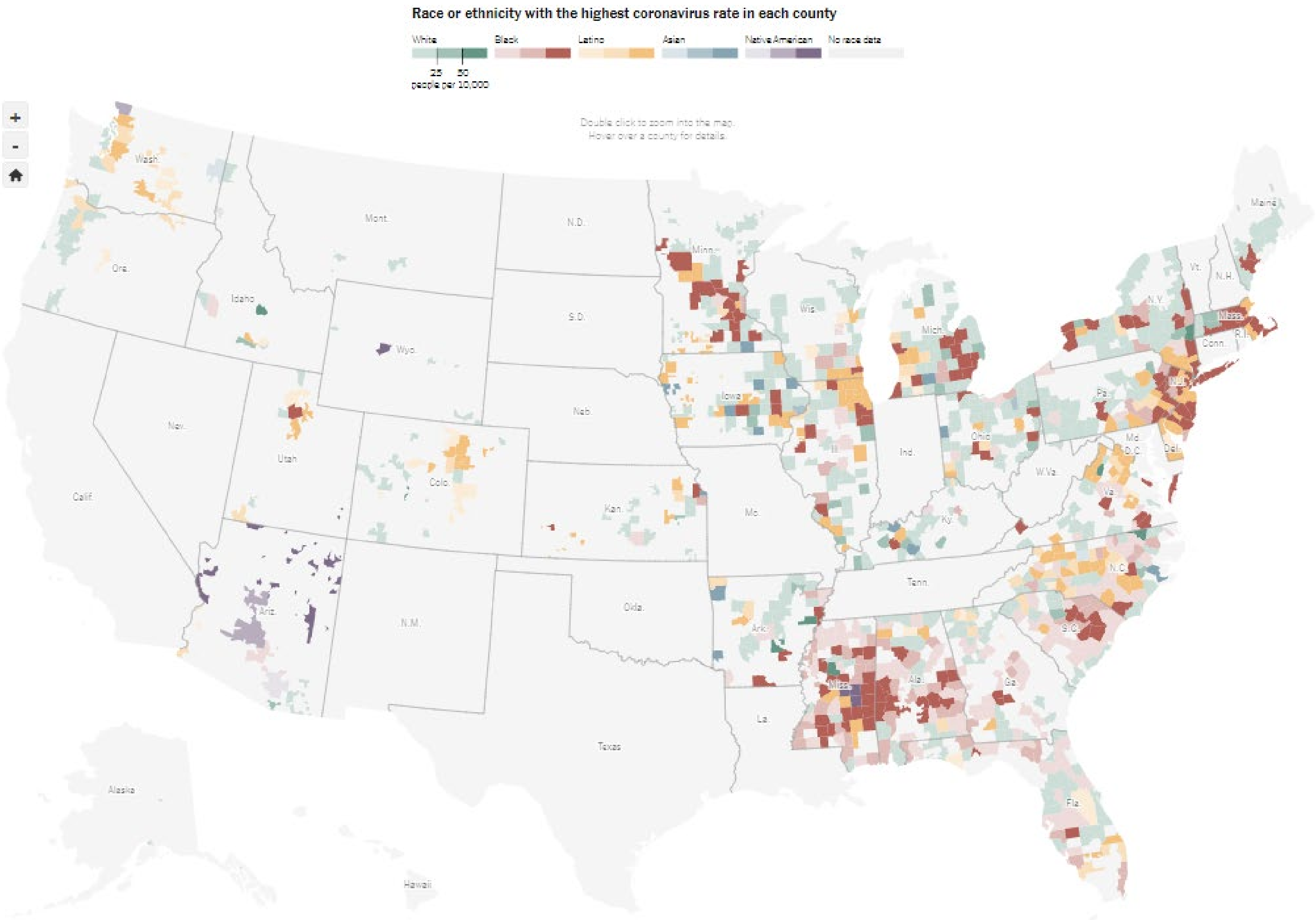
Q: How do freedom of information laws tie into dissemination of disaggregated data?

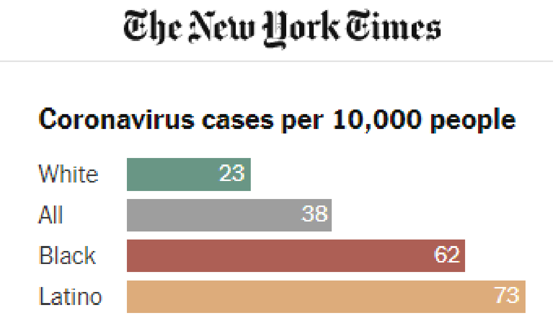
Freedom of Information Laws Reveal Inequities

> “Black and Latino people have been disproportionately affected by the coronavirus in a widespread manner that spans the country, throughout hundreds of counties in urban, suburban and rural areas, and across all age groups”
>
> New York Times, July 6, 2020

https://www.nytimes.com/interactive/2020/07/05/us/coronavirus-latinos-african-americans-cdc-data.html

Freedom of Information Laws





Q: Freedom of information laws and privacy laws come at information sharing from different angles–one often requiring data release; the other more often limiting or even prohibiting data release. How can public health practitioners and attorneys comply with both?

TABLE 5: STATE FREEDOM OF INFORMATION LAWS

Jurisdiction	Examples of records not required to be released[208]
Ohio	■ Medical records ■ Information prohibited from release by other law[209]
Nebraska	■ Medical records ■ Data submitted to Nebraska's prescription drug monitoring program[210]
Tennessee	■ Individually identifiable health information collected, created, or prepared by the department of health[211]
New York	■ Records which "if disclosed would constitute an unwarranted invasion of personal privacy"[212]
Illinois	■ Information that is barred from disclosure by federal or state law ■ Private information, including unique identifiers and medical records[213] ■ Information that is "highly personal or objectionable to a reasonable person and in which the subject's right to privacy outweighs any legitimate public interest in obtaining the information"[214]
California	■ Records, if the public agency can show the public interest in disclosing the particular records to the public is outweighed by a public interest in not disclosing the records[215]

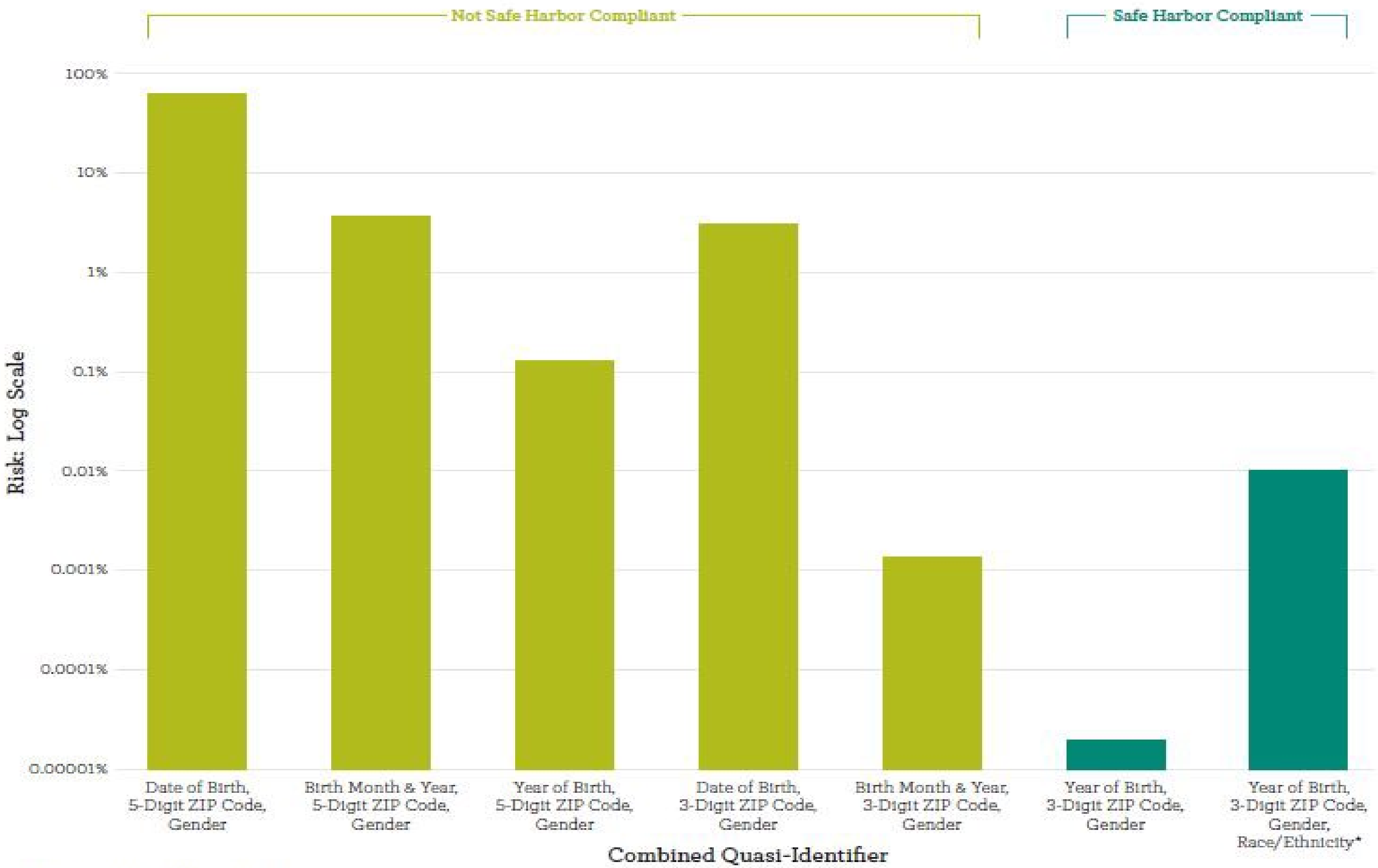
Q: What do we mean by re-identification risks and how are they connected to data disaggregation?

Risk of Reidentification

- Increased re-identification risks from race and ethnicity data with other data points
  - “ability for an interested adversary to use reasonable effort to match details in the de-identified dataset to distinct persons sufficiently to contact them”*
- Biggest risk from dissemination of disaggregated data
- Can vary from dramatically from one state to another
- Even within different areas of a state
- Depending on geographic distributions of racial and ethnic groups

*Sweeney L.. Re-identification risks in HIPAA Safe Harbor data: A study of data from one environmental health study. Technol. Sci. 2017, 2017, 2017082801

FIGURE 4: RE-IDENTIFICATION RISKS: MEDIAN POPULATION UNIQUENESS



* White, Black, Hispanic, Asian and Other

Data source: 2010 U.S. Decennial Census | Graph kindly provided by Daniel Barth-Jones, PhD, MPH ©2013

©Daniel Barth Jones

Q: Does the law provide for de-identification of public health data?

De-Identification Methods

- **HIPAA’s De-identification Methods (45 CFR 164.514)**
  - Expert determination method
    - appropriate expert familiar with generally accepted statistical and scientific principles and methods for rendering information not individually identifiable to determine by statistical analysis that there is no more than a “very small” risk of re-identification
  - Safe Harbor
    - removal of 18 specified identifiers
      - race and ethnicity, gender identity, marital status, and ages in years up to age 89, are not included

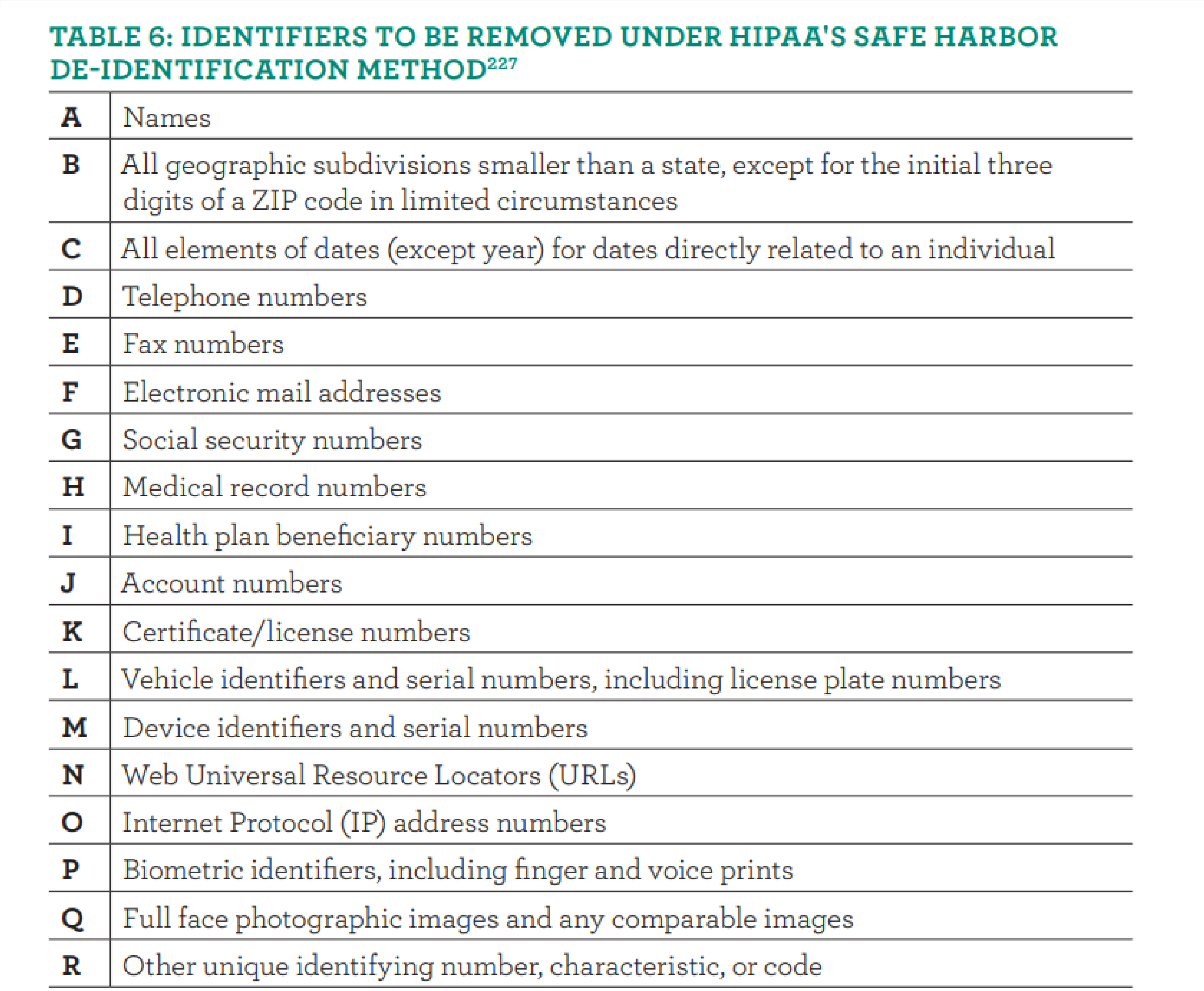


TABLE 6: IDENTIFIERS TO BE REMOVED UNDER HIPAA'S SAFE HARBOR DE-IDENTIFICATION METHOD[227]

A	Names
B	All geographic subdivisions smaller than a state, except for the initial three digits of a ZIP code in limited circumstances
C	All elements of dates (except year) for dates directly related to an individual
D	Telephone numbers
E	Fax numbers
F	Electronic mail addresses
G	Social security numbers
H	Medical record numbers
I	Health plan beneficiary numbers
J	Account numbers
K	Certificate/license numbers
L	Vehicle identifiers and serial numbers, including license plate numbers
M	Device identifiers and serial numbers
N	Web Universal Resource Locators (URLs)
O	Internet Protocol (IP) address numbers
P	Biometric identifiers, including finger and voice prints
Q	Full face photographic images and any comparable images
R	Other unique identifying number, characteristic, or code

Q: Can the re-identification risks created by disaggregation be sufficiently controlled?

Controlling Re-identification Risks

- Expert Determination method
  - Reasoned basis for responsible control and management of re-identification risks
- Statisticians trained in disclosure risk assessment and limitation methods can assess the possible re-identification risks and suggest possible modifications
  - E.g., when more detail is required regarding racial/ethnic categories, the level of detail can be reduced for other quasi-identifiers
    - providing age groups instead of age in years,
    - increasing the size of the geographic reporting units
    - collapsing certain geographic areas together,
    - selectively censoring race/ethnicity in areas where too few individuals exist to allow safe reporting

Q: What are your recommendations to promote dissemination of disaggregated data?

Recommendations to Enhance Dissemination

- State and local health departments should invest resources to:
  - Recruit individuals familiar expert determination method
  - Train all appropriate staff on the safe harbor de-identification method
  - Use of expert determination methods to control risk of re-identification
- State, local health departments should establish clear policies and procedures on dissemination of data
  - Explicit criteria for staff to reference in determining whether to grant data requests
  - Data suppression guidelines
  - Open data release policies
- Lawmakers should create a more cohesive data privacy law framework

Questions?

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Thank you!!