

Legal Tools to Advance Health Equity through Data Disaggregation

Presenters:

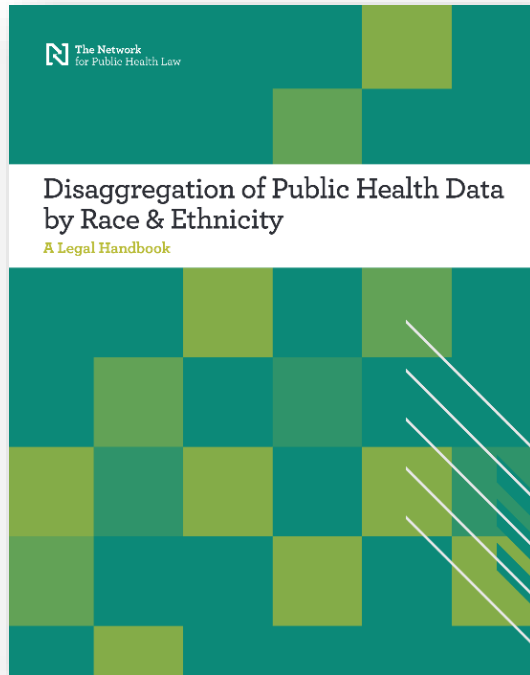
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About the Network for Public Health Law

- 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.



Role of law in collecting and disseminating public health data disaggregated by race and ethnicity

networkforphl.org/disaggregationofphdata

Neither handbook nor this presentation intended to be legal advice. Please make sure to always consult your attorney regarding the specifics of your proposed data-sharing project.

Law: Facilitator or Barrier to Collection of Race and Ethnicity Data in Public Health?

Presenter:

Carrie Waggoner, JD, Director, Mid States Region, Network for Public Health Law

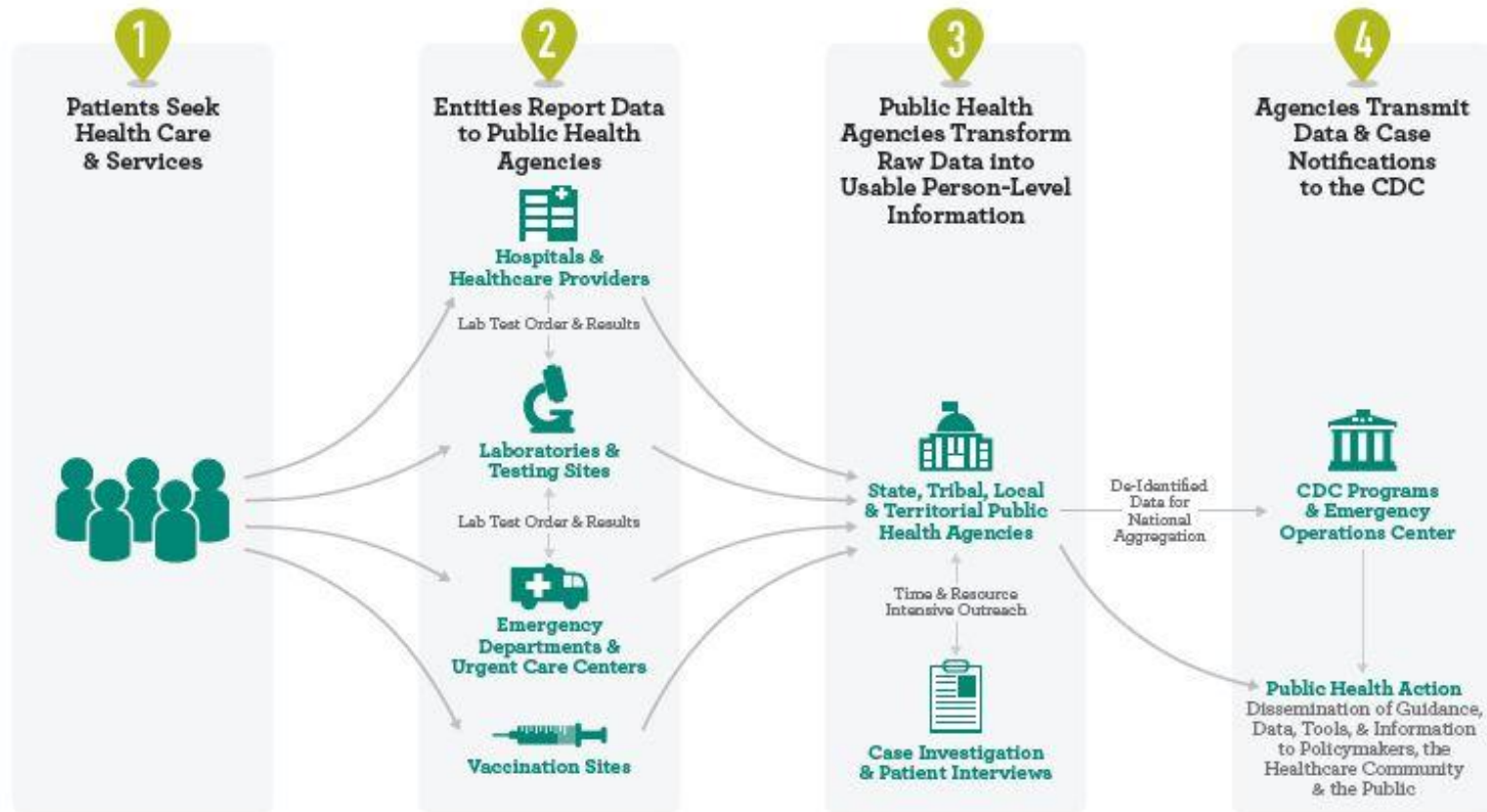
Grounding

- COVID-19 highlighted racial and ethnic disparities
 - Existed prior to and continue
- Data disaggregated by race and ethnicity needed

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
- Tribal law and data sovereignty

Data Flow from Healthcare to Public Health



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

Current Law Permits Collection of Race and Ethnicity Data

- Federal and state laws allow for collection of race and ethnicity in public health data sets
- HIPAA is not a legal barrier to data collection
- ONC's information blocking rule and guidance encourage public health data collection

Non-legal Barriers to Collection of Race and Ethnicity Data in Public Health*

- Patient hesitance to report
- Data reporters not collecting and/or providing
- Technical limitations
- Insufficient guidance, requirements, or standards for data collection
- Limited resources at public health departments

*Addressing Gaps in Public Health Reporting of Race and Ethnicity Data for COVID-19, Council for State and Territorial Epidemiologists, p. 14, Table 1 (2022)

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 (and other) data
- 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 expand 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

Thank you!!

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