Charting a Course for an Equity-Centered Data System:
Recommendations from the National Commission to Transform Public Health Data Systems

National Commission to Transform Public Health Data Systems
April 13, 2022
RWJF, in partnership with others, is working to develop a Culture of Health rooted in equity, that provides every individual with a fair and just opportunity to thrive, no matter who they are, where they live, or how much money they have.
Transforming Public Health Data Systems


The COVID-19 pandemic highlighted many gaps in public health data gathering concerning race and ethnicity. How can data better illuminate the ways in which structural racism and other forms of discrimination drive health inequities?
“If we are to become a nation that truly values health equity, public health data must reflect fairness, justice, and inclusion as fundamental requirements.”

- Dr. Richard E. Besser, President and CEO, Robert Wood Johnson Foundation
Commission Mission

- Established by the Robert Wood Johnson Foundation
- Led by Dr. Gail Christopher of the National Collaborative for Health Equity
- 16-member Commission with experts representing multiple sectors – healthcare, community advocacy, government, business, public health, and others
- Charged with reimagining how data are collected, shared, and used and identifying the investments needed to modernize our public health data infrastructure and improve health equity
Center Health Equity
Summary of Recommendations

Center health equity and well-being in narrative change

Prioritize equitable governance and community engagement

Ensure public health measurement captures and addresses structural racism and other inequities
Overarching Recommendation #1

Center health equity and well-being in narrative change

- Develop a competencies framework to increase data literacy for various stakeholders about the importance of equity considerations in data systems.
- Challenge perceptions about what constitutes public health data and who has access to them.
Prioritize equitable governance and community engagement

- Build efficient and interoperable data systems with guidance on standardized data collection and rollup of granular categories, if needed, to generate comprehensive, complete, and timely data. Collect data with adequate granularity across population groups and geographic levels that are useful at the community level and can be aggregated and disaggregated.
Overarching Recommendation #3

Ensure public health measurement captures and addresses structural racism and other inequities

• Collect accurate, relevant community-level data that support small-area estimates so that communities and local health departments can better prioritize and address local health challenges and measure progress toward healthier communities.
Call to Action

- Regularly connect public health data to local communications (i.e., what is happening in the community and how it relates to overall community well-being, or the impact of inequity).

- Ensure the local voice is represented not only in public health data, but in positions of authority responsible for making sense of the data and informing decisions.

- Explore data-sharing collaborations across government and civil society that can more consistently generate public health data to support equity considerations and advance innovative public-private collaborations on data and analysis.

- Lead multi-sector collaboration around public health data sharing to improve the timeliness and quality of data to strengthen local decision-making.

- Advocate for and prioritize modernization efforts and data sharing within and across the public health system to ensure that local data can inform emerging public health concerns at the regional, state, and national levels in real time.
Short-Term:

- Provide input to the CDC to ensure that governance and improved infrastructure robustly support local goals and needs.

- Governance of data sharing should be driven at the local/state/tribal level and should inform what information can be shared, with whom, and under what conditions.

- Establish a community advisory council to provide guidance on public health data sources, uses, and interpretation of data and ensure genuine community engagement.

- Map the power, expertise, and authority dynamics that shape public health data systems and engage all stakeholders as partners in the transformation.

- Develop messaging aimed at different audiences about the value of public health data and modernizing the public health data system.
Recommendations

Long-Term:

■ Provide supports to a local data workforce that can tailor data collection efforts locally and employ small-area estimations and other techniques.

■ Use a Community Commons model as a data repository to help communities engage with and promote data that are compelling, advance a public health narrative, support action, and demonstrate that health equity can be improved.

■ Enable active and sustained community engagement in public health data discussions and decisions around public health data systems design, content, and use.

■ Highlight the important role of collecting and analyzing public health data for implementing equitable public policy.

■ Continue to emphasize the value of public health data and its linkage with community and national progress.
RWJF awarded an initial $50 million in funding to create a more equitable national public health data infrastructure including projects to:

- **Transform local data environments** to eliminate systemic barriers and provide more timely, accurate, and complete information

- **Build community-academic partnerships** with historically black colleges and universities in the Gulf Coast region to address health equity

- **Promote more meaningful data disaggregation** beyond broad racial/ethnic categories to offer a more complete picture of health disparities
Thank You