

Adopting Equitable Data Practices in Public Health Analysis and Surveillance



Kathi Lynch, MS

Holly Sienkiewicz, DrPH



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Disclosures

The authors declare that neither has relevant or material financial interests that relate to the research described in this presentation.





Common Ground
It's who we are and what we help build



Our Work

- Community learning and voice
- Health care workforce
- Health condition improvement
- Health planning
- Mental health
- Older adults
- Whole child health



Data is power. It drives decisions, influences funding, and can change lives...for better or worse. Implicit biases influence the decisions we make, including data decisions. Biases infiltrate data, potentially skewing or discrediting findings.

In what ways does bias exist?

- A demographic question on gender identity that only provides “male” and “female” as choices
- A household composition question with “family with children” and “single adult with children” as choices
- A race question that only allows one choice to be selected

What is data equity?

Principles that utilize an equity lens to consider the ways data is collected, analyzed, interpreted, and disseminated

- Data is not objective
- Data can create and perpetuate power dynamics
- Data equity needs to be considered throughout the data life cycle

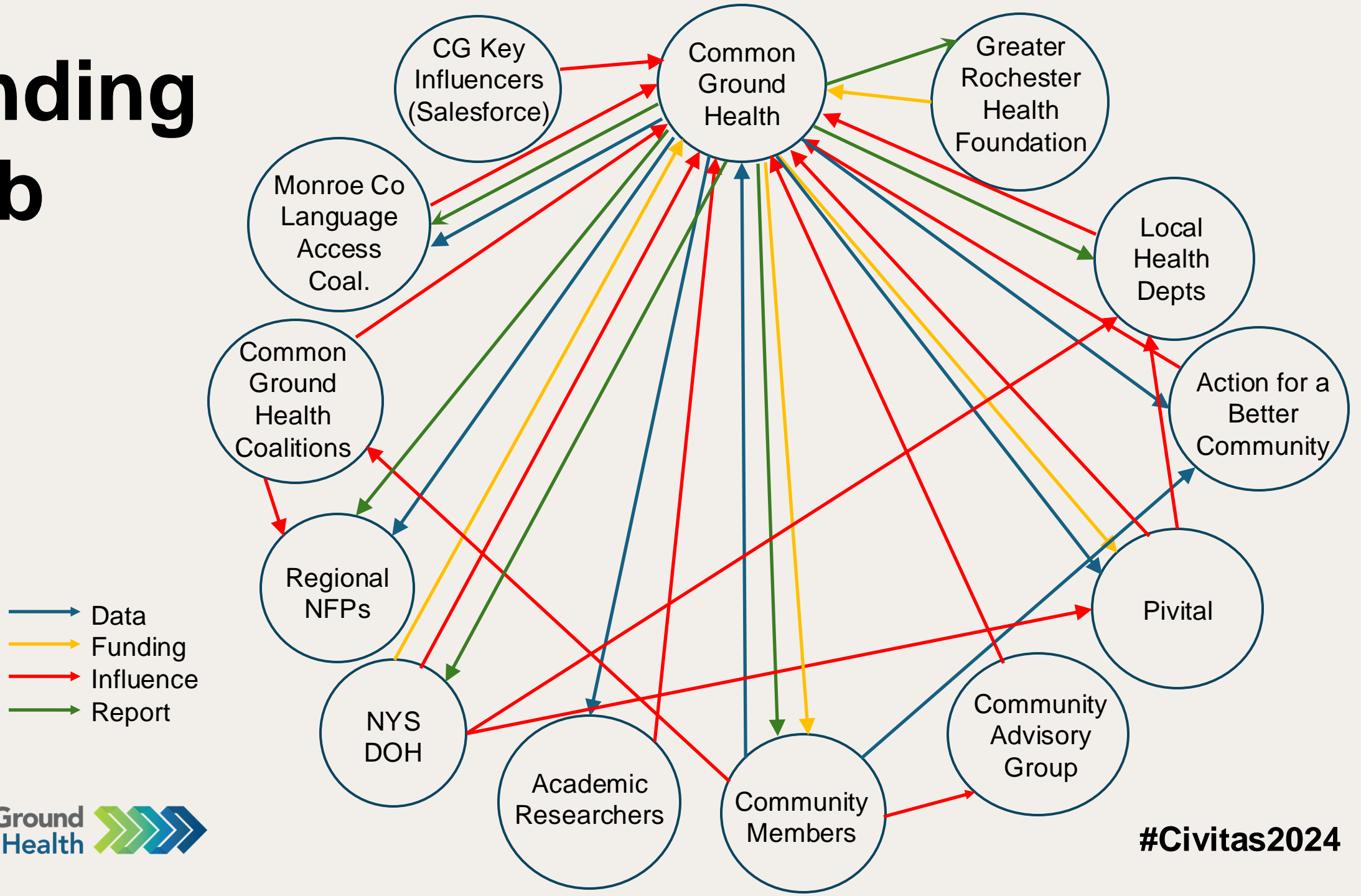
To Integrate Equity

Systematically question biases and power dynamics at each phase of a data project:

1. Funding
2. Motivation
3. Project design
4. Data collection and sourcing
5. Analysis
6. Interpretation
7. Communication and distribution



Funding Web



Motivation Statement

Common Ground Health's mission is to bring greater focus to community health issues.

With the My Health Story project, we will do so by monitoring health data and health equity trends, including the impact of the COVID-19 pandemic, obtaining data not found in other sources to better inform actions to address disparities, and further examining the relationship between health outcomes and social determinants of health.

Project Design

- IRB requirements
- Granularity of data collected
- Partner involvement
- Resident engagement
- Recruitment strategies
- Incentives





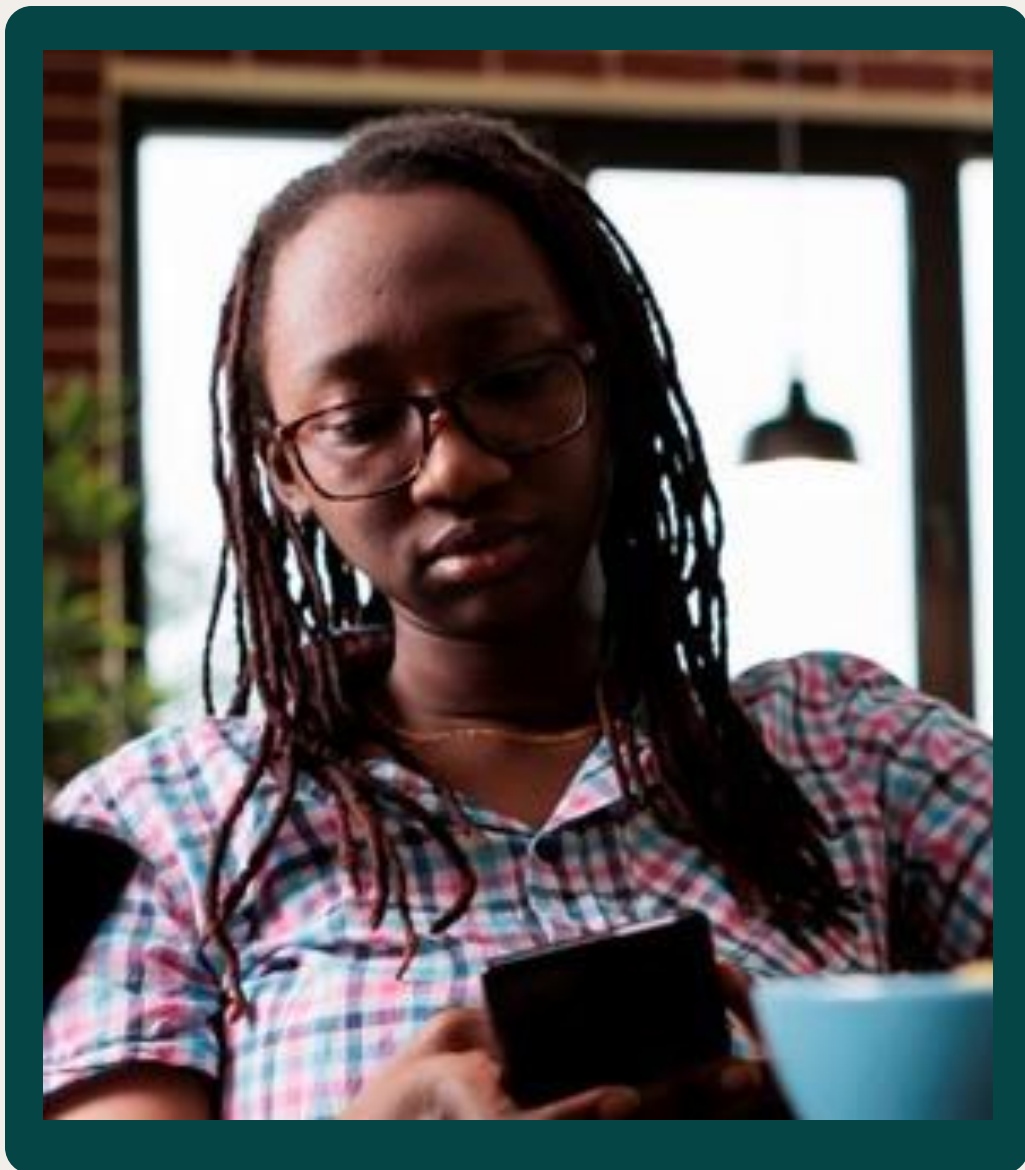
Intentional Engagement

- Iterative process of refining survey questions
 - Partner Organizations
 - Residents
- IRB training
- Community Advisory Group

Data Collection and Sourcing

Create a data biography and be specific!

- Who is included in this dataset?
- Who is excluded from this dataset?
- What is the reach of this dataset?
- What are the limitations with how data was collected?



Data Biography Key Information

Dataset Name: Behavioral Risk Factor Surveillance System

Dataset Collection Year: 2021

Select from common dropdown

options or write in:

Other/Notes

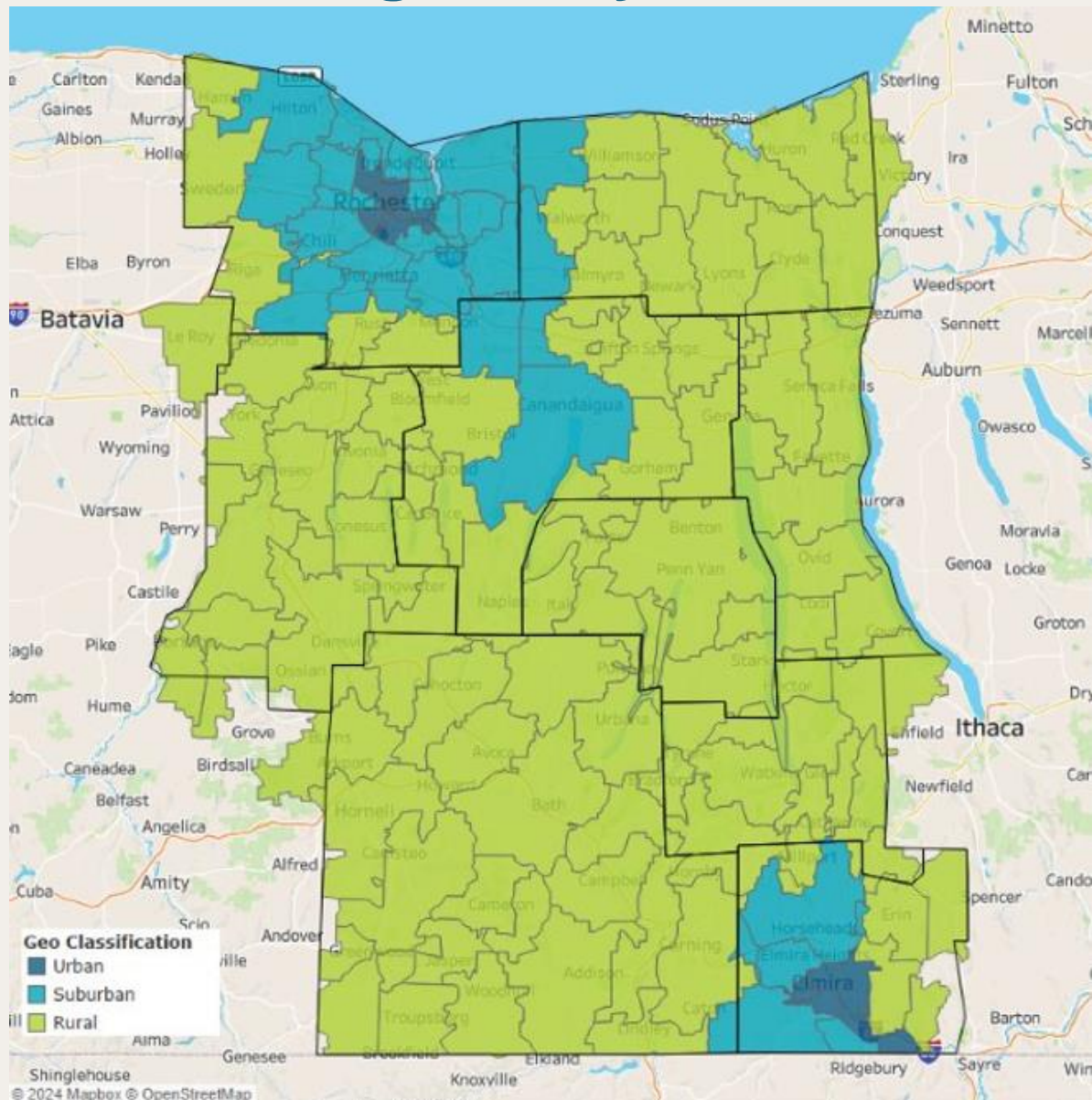
What		
4. What types of data was collected?	Demographics, health assessments, optional modules	
4.1 Complete details of individual variables in attached sheet	Variables Sheet	
4.2 What social identity data was collected?	Sex, over 18, race, sexual orientation, employment, income, number of children, veteran, marital status, education, disability, transgender	Transgender, sexual orientation, and disability are optional by state
4.3 Complete the details of the social identity and demographic variables in attached sheet	Demographics	
4.4 Were any questions were answered by the enumerator rather than directly by the respondents?	All questions were answered by respondents	
5. What skip patterns were used?	Eligibility or survey or health section eligibility	
5.1 Could the skip patterns used introduce potential bias?	Yes, definitely (For example, if someone replies that their sexual orientation is homosexual, do they get skipped in asking about parenthood.)	For the question, "Are you male or female?," if someone responded don't know, unsure, or refused, the survey was ended. With a binary response choice intersex respondents or those beyond the binary were excluded.
declined to participate?	Yes, for all	Limited to type of phone, refused, or eligibility
3.2 What groups of people were intentionally not included?	People under 18, not in a private residence or dorm, patients staying in-hospital, people not binary male/female sex identification	
3.3 What groups of people were accidentally not included?	Those without phones or updated public phone records or unable to use a phone	

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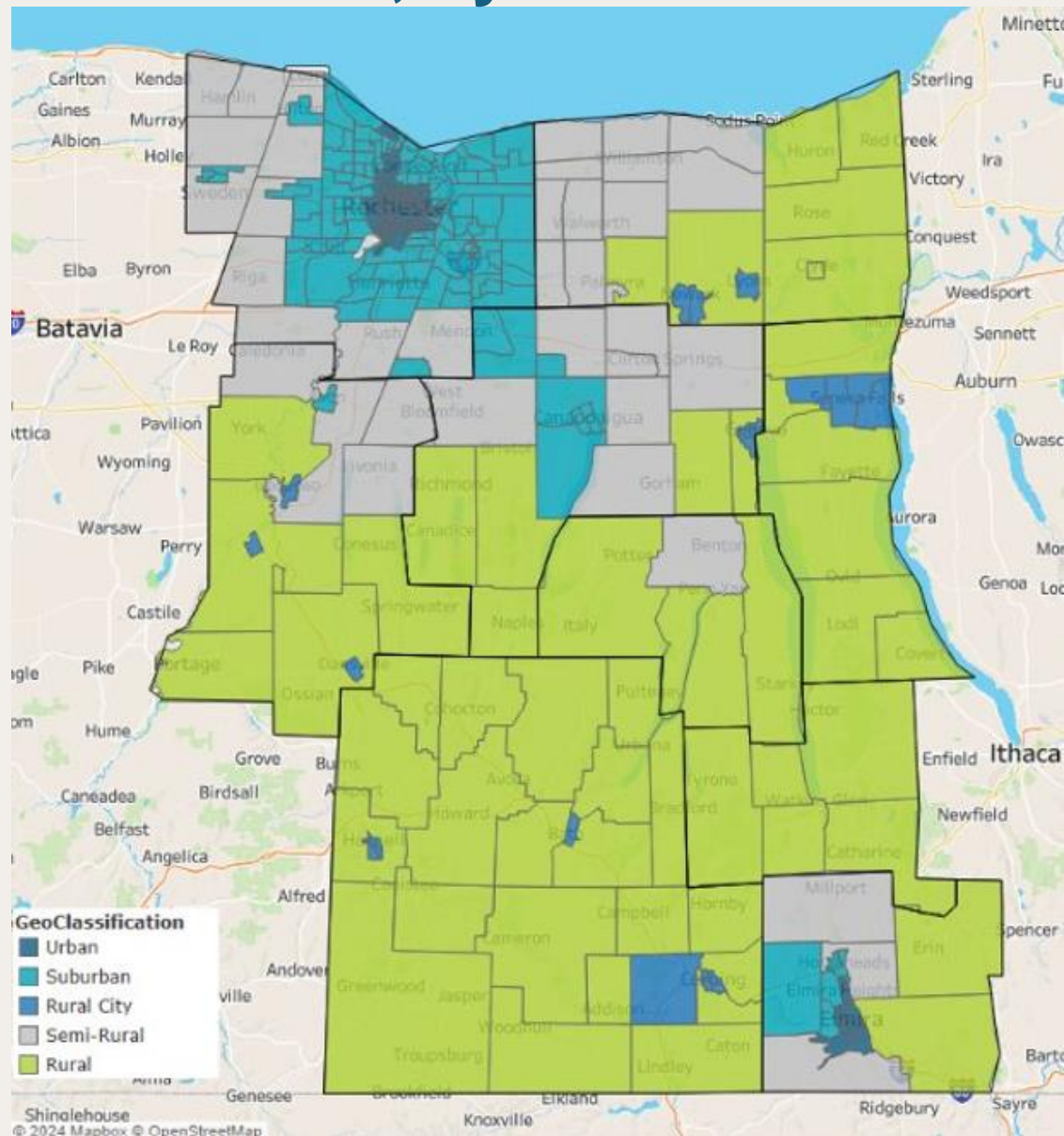
Analysis and Interpretation

- Data quality checks
- Addressing spam and inauthentic records
- Analyses and weighting
- Interpretation checks
 - Staff with diverse perspectives and experiences
 - Coalition members
 - Partner organizations

Original, by ZIP code



New, by census tract

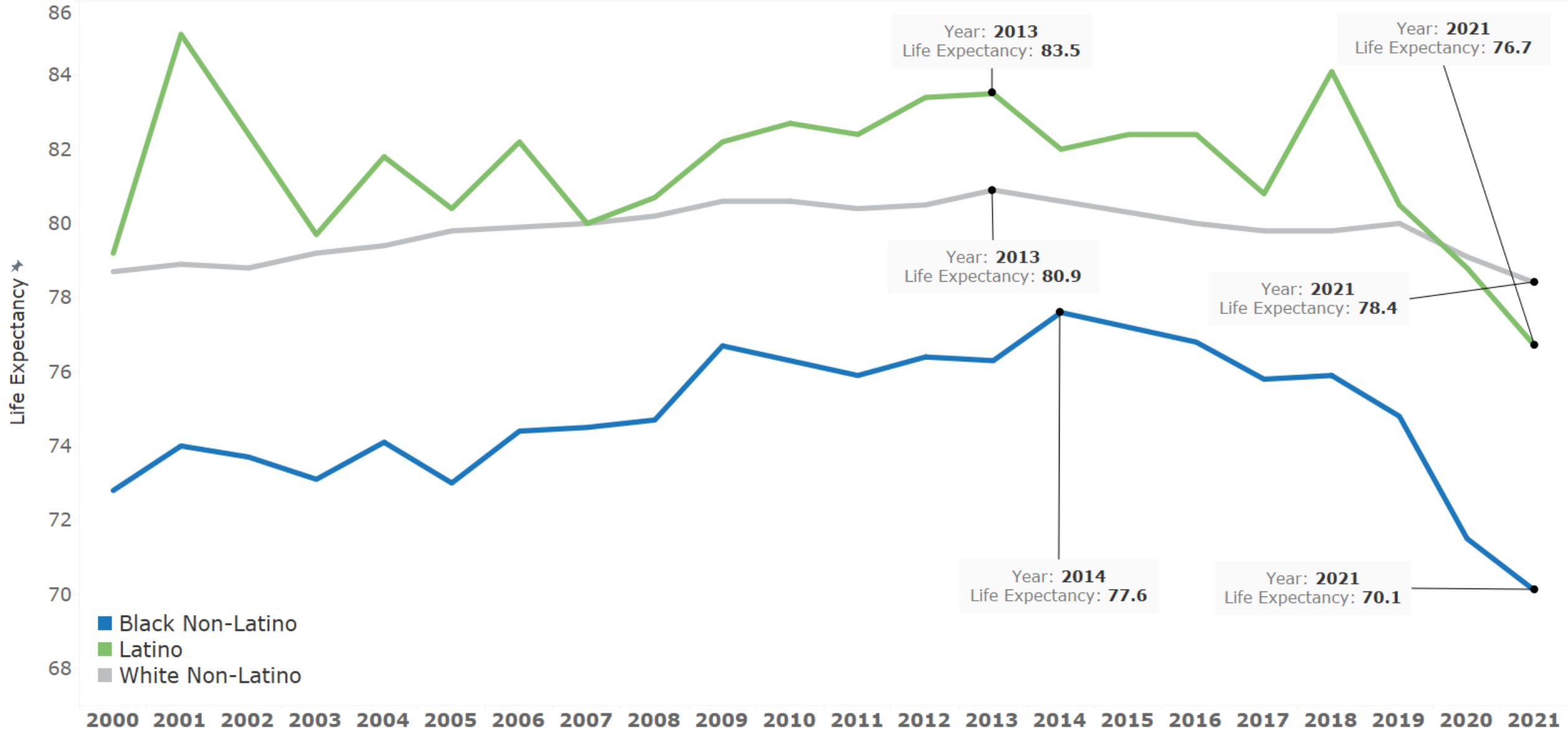


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Communication and Distribution

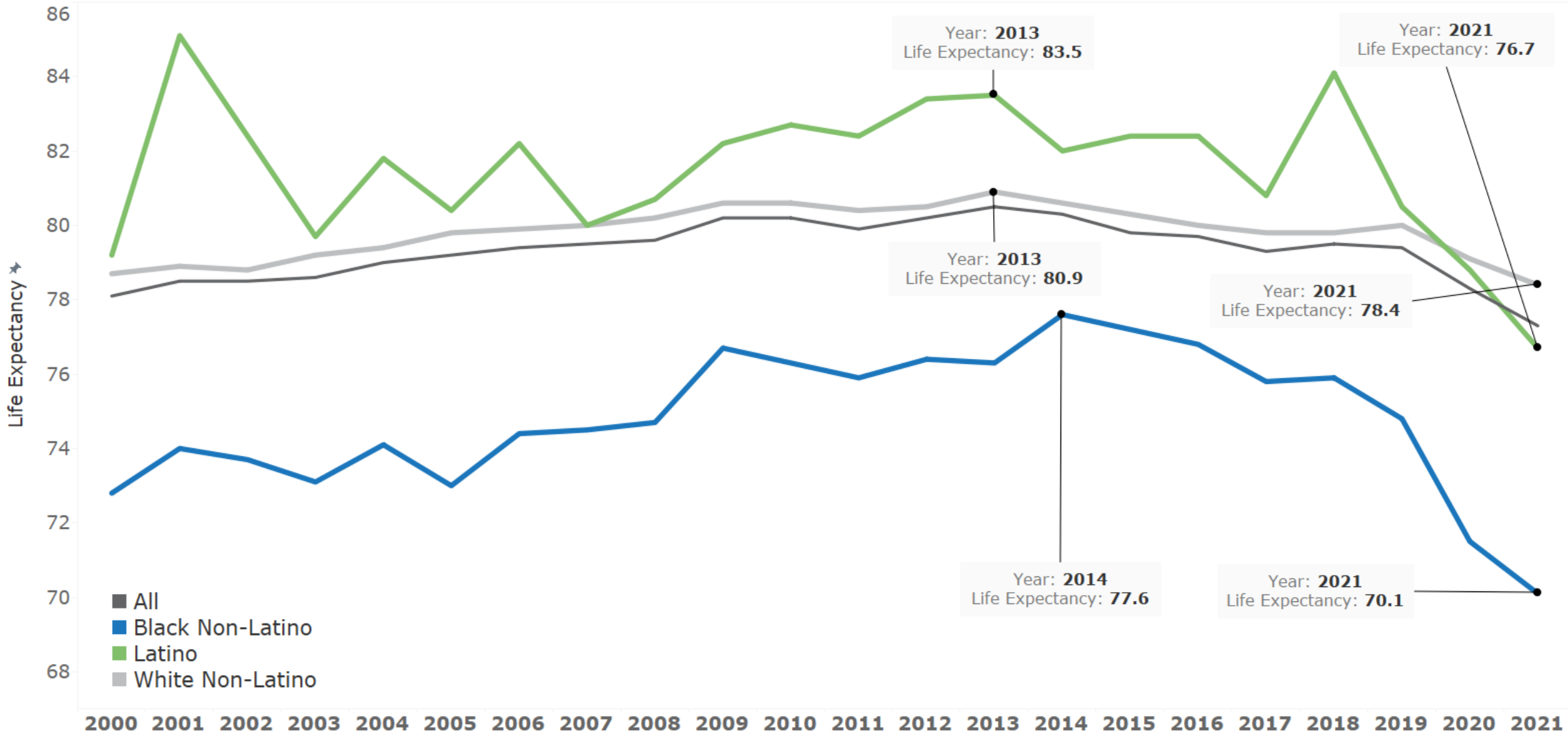
- Who creates the narrative?
- Who reviews and has editing rights?
- Who has access to the data and at what level?
- Who's centered (or not) in data visualizations?

Life Expectancy in the Finger Lakes by Race/Ethnicity



Life Expectancy in the Finger Lakes by Race/Ethnicity

updated



Integrating Equity

Pitfall	Strategy
Non-inclusive Fields & Survey Responses	<ul style="list-style-type: none">• Iterate response options w/ partners• Test with residents
Lack of Transparency	<ul style="list-style-type: none">• Detailed data biographies• Published methodologies
Assigning Labels	<ul style="list-style-type: none">• Inclusive conversations w/ documented decision points
Data Hoarding	<ul style="list-style-type: none">• Share data as much as terms allow

“If we do not address power dynamics in the creation of research, at best, we are driving decision-making from partial truths. At worst, we are generating inaccurate information that ultimately does more harm than good in our communities. This is why we must care about how research is created.”

– *Chicago Beyond*



Thank you!

<https://weallcount.com>

Kathi Lynch

585-224-3155

Kathi.lynch@commongroundhealth.org

Holly Sienkiewicz

585-224-3166

holly.sienkiewicz@commongroundhealth.org

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